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University  
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Sheffield.

**Using social constructivist grounded theory to explore how people come  
to use hospice day care services: a theory of transience and transition**

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F. Wilson

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**Using social constructivist grounded theory to explore how people come to use hospice day care services: a theory of transience and transition**

**By:**

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# Abstract

## **Using social constructivist grounded theory to explore how people come to use hospice day care services: a theory of transience and transition**

### **Background:**

Choice and autonomy are key principles within palliative care in the UK and are enshrined within a number of health policy documents from 2008 onwards. However, it is unclear how people enact choice around their end of life care, particularly with regard to using hospice services.

### **Aim:**

This study aims to explore patient, carer and staff perceptions of choice and decision-making in accessing a hospice day unit.

### **Method:**

This study uses a social constructivist approach to grounded theory to explore perspectives. Fifteen patients and six carers participated in one-to-one semi-structured interviews using a PICTOR approach. Twenty staff, including hospice and referring staff, participated in nine one-to-one interviews and two focus groups. Transcribed interviews were analysed using an iterative process of coding, memoing, and development of core categories.

### **Results:**

The overarching theme of 'transience and transition' captures that access to a hospice day unit is an uncertain and transient journey, with the ultimate transition being death. Staff perceived their role as one of intuitively 'being there', however professional constructs of need indicated a more 'managed' approach to supporting care. Patients responded to the transient nature of transition by focussing on the certainties of living and dying, particularly supporting others and managing everyday concerns. Carers experienced transience and transition with a sense of presentiment, exclusion and loss.

Health literacy around palliative care and choice was limited in all three perspectives illustrating mixed understandings around hospice services.

**Conclusion:**

Essentially dying is not a passive transition but requires effortful and active engagement in supporting others, whilst also managing the requirements of everyday living whilst dying. The disruptive and emotional transition to hospice care challenges notions of choice, decision-making capacity, resulting in a 'managed' approach to care decisions. Acknowledging the uncertainty of dying whilst supporting individuals to manage everyday life, as well as an emphasis on relational care would help to meet patient and carer needs. Greater transparency, integration and awareness of services could facilitate transition and agency.

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**Fiona Wilson**  
**2017**

**Presentiment is that long shadow on the lawn**  
**By Emily Dickinson**

Presentiment is that long shadow on the lawn  
Indicative that suns go down;  
The notice to the startled grass  
That darkness is about to pass.

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## Glossary of Key terms

<b>ACP</b>	Advance Care Planning: Discussion of values, goals and preferences of patients requiring long term and end of life care. This is not a formal legal document but a means of documenting patient references of care. ACP aims to provide care that meets the goals and preferences of patients requiring long term and end of life care. Advance care planning may include the appointment of a friend or individual to support care wishes should mental capacity decline.
<b>ADRT</b>	Advance Care Directive to Refuse Treatment: An individual may make an advance decision to refuse treatment. The individual should have capacity at the time of the discussing and drawing up an ADRT agreement. This is a formal documentation of wishes around refusal of treatment. The clinical team when making best interest decisions about care must consider any ADRT.
<b>DNACPR</b>	Do Not Attempt Cardiac Pulmonary Resuscitation: Non-resuscitation in the event of a cardiac or respiratory arrest. The decision to complete a DNACPR order is a clinical decision of patient best interest. It is good practice for proposed DNACPR orders to include discussion with the family and patient, and before being clearly documented.
<b>MCA</b>	Mental Capacity Act ( 2005): Individual assessment of mental capacity in deciding care decisions through a diagnostic test to assess possible impairment or disturbance of mental function and a functional test, which assesses ability to understand, retain, process information, and communicate wishes.
<b>PPC</b>	Preferred Priorities of Care: A discussion tool focussing on preferred priorities of care important to individuals, particularly focussing on place and context of care. Informally documented and not legally binding.
<b>LCP</b>	The Liverpool care pathway: A tool developed in the 1990s to foster a high standard of care for patients in the last few days or hours of life. A number of concerns emerged about the use of the tool in practice, leading to a review entitled "More Care: Less Pathway" (Neuberger 2013). This identified a number of concerns including primarily communication, training and the difficulty of diagnosing the dying phase. The review advised phasing out of the tool by 2014, and recommended that a range of professional and regulatory bodies review standards of care for future practice.
<b>GSF</b>	Gold Standards Framework: Developed by Dr Keri Thomas and supported by NHS, Macmillan and other organizations to improve standards of care at end of life. Provides a range of accredited training and resources to support care delivery in primary care and acute care including care homes and domiciliary care. See <a href="http://www.goldstandardsframework.org.uk/">http://www.goldstandardsframework.org.uk/</a>
<b>SPARC</b>	Sheffield Profile for Assessment and Referral for Care (SPARC) tool: This 45-item questionnaire aims to provide an holistic assessment of patient care needs across nine domains. The tool aims to support the early management of supportive and palliative care.
<b>EPaCCS</b>	Electronic Palliative Care Coordination Systems (EPaCCS): Introduced in 2011 to develop a means of recording and sharing people's preferences across care systems and enabling coordination and access to services.

# Chapter 1: Introduction

## 1.1 Introduction

Choice is foregrounded as a major policy objective within the context of palliative and end of life care policy in England from the “*End of Life Care Strategy*” (DH 2008) (Department of, 2008) to the “*Our Commitment to you for End of Life Care*” (DH 2016). An agenda of choice has implications for service delivery and captures the growing focus on shared decision-making within health care generally. Despite an agenda of choice, however it is uncertain how people make decisions around end of life care. This study uses a social constructivist grounded theory (SCGT) approach to explore how people come to use hospice services, (specifically a hospice day service) within an agenda of choice, decision-making and advance care planning.

The demographic shift toward an ageing population and increased longevity has led to a predicted global increase in palliative care needs. (Higginson 2012). Palliative care is therefore described by Clark et al. (2015) as an international ‘public health and human rights issue’. This study contributes to the on-going debates around palliative care delivery, capturing the tension between a policy emphasis on individual choice and empowerment against the need to manage resources within an insecure economic climate. Two publications have contributed to the current evidence base around choice in palliative care, (Wilson et al. 2011, and Wilson et al.2013, see Appendix 2 and 3). This thesis also led to a collaborative public health initiative between the university and the hospice to raise awareness of death and dying through a number of death café events.

## 1.2 Personal and professional motivation

The genesis of this study is both personal and professional, motivated by my experience as a nurse within a local Northern UK hospice and my work as a

research associate on a number of health and social care studies over the last fifteen years or so. Nursing skills particularly seem to hone skills of observation, not just in a clinical context but almost habitually, whilst research develops a predisposition to question and analyse, and both habits seem to permeate reflexively into everyday life. However, I did not consciously reflect, until the study was well underway, that one of the practical reasons for working at the hospice was to supplement my income in order to visit my mother some distance away in order to support her during her two-year illness until her death in 2007. The hospice work was stimulating and rewarding but in the background I was watching my own mother shift from living to dying within the context of a medical versus palliative care system in which notions of individual choice and autonomy were presented as confused and confusing. Both she and those providing care, including the family and the health professionals supporting her, resisted hospice referral. The issues appeared to focus on firstly, the hospice as a place that one would not choose to attend (being an ominous sign that death is imminent), the number of beds available and the health professionals' inability to engage both my parents in discussions around her impending death. Dialogue was challenging, for a number of reasons including professional assessment of needs, and the emotionally charged nature of the interactions, as well as some confusion around who was in charge of her care (the Macmillan specialist nurse, the oncology consultant or the General Practitioner).

Despite my efforts to have mother referred to the hospice day unit, (which I strongly felt would be beneficial) and for her to accept the referral, she suddenly deteriorated and died in an acute hospital in late 2007. It is difficult to conclude whether this was a better or worse death than she may have received using alternative care services such as a hospice. Perhaps from her perspective, (in which she often articulated that she was 'battling with cancer') she died 'fighting', and therefore experienced death on her own terms. However, for myself, then working within the hospice setting, it felt as though her death had been poorly handled, and that she had somehow 'missed out' on a more holistic approach to care which might have served her and my father better in helping them come to terms with her dying and support their visible distress. At the

same time, I was working at the hospice and listening to nursing handovers. 'Missing the window' was a phrase used to describe patients who were admitted as in-patients either too late or too early, with implications for discharge and wellbeing, raising questions around whom, how and why individuals were referred to the local hospice. Later, in 2008 the Department of Health (DH 2008) published the 'End of life care strategy: promoting high quality care for adults at the end of life' which aimed to progress a coordinated system of standards and pathways to address issues of choice and care at end of life.

The National End of Life Care Strategy (DH 2008) formalised the work of the National End of life Care Programme (2004) to ensure that end of life and palliative care was an established priority within health and social care. Borgstrom (2016) argues that the strategy was rooted within the hospice movement in the UK and was central in establishing a framework for palliative care within wider health care settings. A key principle within this strategy was the assumption that patient choice and autonomy are fundamental to a 'good death' stipulated in the aim "to ensure that people's individual needs, priorities and preferences for end of life care are identified, documented, reviewed, respected and acted upon wherever possible" (DH 2008, p.33). The strategy signposted a number of guidelines and standards for the delivery of palliative care. These included the Liverpool care pathway for the dying (Marie Curie Palliative Care Institute (2009)), and additional protocols for the guidance of advance care planning, including preferred priorities for care documentation and consideration of Do Not Attempt Cardiac Pulmonary Resuscitation (DNACPR) orders. The Mental Capacity Act (Great Britain 2005) was central in providing a supporting mechanism to assess individual capacity to make decisions. The End of Life Care Strategy (DH 2008) also linked to the Gold Standards Framework Centre founded by Professor Keri Thomas in 2000, to provide a 'gold standard' in integrating a personalized system of end of life care in primary care settings (Gold Standards Framework Centre, 2017). Borgstrom (2016) argues that the emphasis on choice and control within the strategy complemented the context of a neo liberal agenda that emphasized self-determination and choice within health and social policy generally. The strategy was a landmark in care delivery both nationally and internationally and

coincided with a general drive toward shared decision-making within clinical practice (Rapley & May 2009).

There are a number of challenges to planning one's own care when facing end of life. Operating choice around care at end of life is likely to be an emotionally charged and complex activity in which rational decision-making is challenging (Emanuel 2012). Furthermore, Cox et al. (2013) draw attention to public uncertainty around the meanings of terms such as 'palliative', and 'end of life care'. Confusion over care terminology and services is likely to challenge capacity to make informed decisions when facing end of life. Despite calls for greater engagement in planning and choosing where and how one would like to be cared for, there is also recognition that dying is an uncertain process (Cox et al. 2013). Paget & Wood (2013) argue that 'people's final journey must be one of their own choosing', whilst also acknowledging that preferences for place of care appear to be fluid. Similarly, Wood & Salter (2013) identify that preferences shift as needs adjust through the dying trajectory. Furthermore Gomes et al. (2011) identified that whilst the majority of people would prefer to die at home, hospice care presents as a second choice, with preference for hospice care increasing with age but also with experience of caring for someone else at end of life. Operationalization of choice at the end of life is therefore likely to be complex and shaped by a number of factors including experience of care, shifts in care needs, and public understandings of what palliative care is, and what hospice care offers.

Currently over two hundred hospices in the UK provide a range of specialist palliative care services including inpatient care, day hospice care, and community based care, hospital support, outpatient support and bereavement support (Hospice UK 2016). The majority of this care is community based, with day hospices providing only 10 per cent of the care. Hospice UK (Casper 2016) notes that there are 'multiple access points' and that patients access a range of hospice services, including day centres and inpatient care. Care is free at the point of delivery with only a third of care funded by the NHS (Casper 2016) and the remainder through charitable fundraising. The sector is therefore partly

independent with some local variation in service provision, although Hospice UK operates as a national advisory organisation.

There are questions around who accesses hospice care. Currently the majority of referrals are for cancer (Casper 2016) but there is recognition of unmet palliative care needs within a range of long-term conditions and a shift toward providing support for those with conditions such as heart failure, chronic obstructive pulmonary disease and a range of neurological conditions. Howarth (2007) argues that hospice services tend to serve a predominantly white, middle class and Christian population. Similarly, Dixon et al. (2015) report that Black Asian and Minority Ethnic groups (BAME) are less likely to access hospice services, whilst issues of cost and demand appear to encourage home care or care settings for older people. The demographic of who access hospice services therefore raises questions around equality and equity of access.

The emphasis on patient involvement in choice and decision-making would therefore seem to belie the complexity surrounding issues of choice and decision-making in accessing hospice care as outlined above. It is unclear how people enact choice around end of life care, particularly with regard to using hospice services. This study therefore aims to use a constructivist approach to explore patient, carer and staff perceptions of choice and decision-making in accessing a hospice day unit.

This thesis uses a social constructivist grounded theory (SCGT) to explore the factors that shape access to a hospice day service and presents a study of how staff, patients and carers negotiate care decisions. The thesis adopts the following structure:

**Chapter two** outlines the key concepts around hospice care, and terminology around palliative and end of life care, and provides a critical review of choice and autonomy.

**Chapter three** presents a literature review of decisions and choice in relation to hospice care. This study acknowledges that there is dispute regarding the

positioning of a literature review within social constructivist grounded theory (SCGT).. This study however, adopts Charmaz's (2006) position that a literature review is often required in line with a research protocol but can also provide an overview and allows for sensitivity and awareness of preconceived understandings of the social world. Mindful of the conundrum that familiarity with the literature can be both positive and negative within a SCGT enquiry, the literature review presents two distinct phases. Phase One presents an initial review conducted at the beginning of this study in January 2010, and Phase Two provides an update of literature occurring over the lifespan of the study (March 2010-2016).

**Chapter four** sets out the epistemological approach of social constructivist grounded theory and rationale for adopting in this study. The study design involves a triangulation of patient, carer and staff perspectives and provides an overview of conducting research within a palliative care setting, the use of Pictor within interviews, and consideration of ethical issues and researcher reflexivity in the practice of 'doing' research.

**Chapters five, six and seven** present the findings from staff, patient and carer data. The overarching theme of transition and transience illustrates that whilst staff conceptualise their role in supporting patients and carers as 'being there' on a journey, the experience of patients and carers is more uncertain and captures a sense of transience, presentiment, exclusion and loss. For patients hospice referral is a shock and precipitated by crisis. Patients focus on the certainties such as supporting others and funeral planning, rather than future care planning. For carers, the hospice represents the 'end of the line' experienced as loss and isolation. Health literacy was limited in all three perspectives suggesting mixed understandings around hospice services and palliative care generally.

**Chapter eight** provides a discussion and interpretation to the findings. This chapter contextualises the findings within the current policy and evidence base with a particular focus on Meleis et al's (2000) model of transition theory within nursing. This model provides a template for structuring the discussion and

enables an examination of the conditions that enable or inhibit transition and the implications these hold for choice and decision-making around hospice and palliative care.

**Chapter nine** explores the strengths and limitations of the study using Charmaz's (2006, 2014) criteria of originality, credibility, usefulness and resonance. A study summary reiterates the uncertain and transient nature of death and dying and implications for decision-making in palliative care. Finally, the study explores the implications for practice and recommendations for future research and an overall summation concludes the study.

## Chapter 2: Key concepts

The focus of this study is to understand how people come to access hospice services and make decisions about care within an agenda of choice, decision-making and advance care planning. This chapter provides a background to palliative and hospice care, and critically explores the concepts of choice and autonomy in the field of palliative care.

### 2.1 Definitions of palliative care

A number of researchers, including Payne et al. (2013) and Cohen & Deliens (2012) argue that palliative care needs are set to rise exponentially with the rise in longevity and increasing co morbidities. Clark (2016) describes access to palliative care as a basic 'human right'. Defining the 'palliative care patient' is however challenging, reflecting a lack of consensus around definition and target population (Zamon et al 2016). Definitions are problematic in that 'palliative', 'end of life' and 'terminal' care tend to centre on life expectancy, which in itself can be uncertain (Van Mechelen et al. 2017). Differences in definition exist in terms of international comparisons (Zaman et al. 2016) reflecting an heterogeneity of different service models (Bereton et al. 2017) so that even terms such as 'hospice' are used differently in different contexts (Seymour & Cassel 2017). Zamon et al. (2016, p.76) suggest that the term 'palliative' became more evident in Britain and the USA in the mid-1970s, reflecting the historical background of palliative care.

Even within the UK, the terms 'end of life', 'palliative' and 'supportive' care are interchangeable and inconsistent in definition. Zaman et al. (2016, p.73) capture this ambiguity writing that: "if palliative care is not necessarily synonymous with end of life care; the former is certainly a part of the latter." Ambiguity is reflected in a number of definitions for example, the NHS Choices website (2015) describes 'end of life care' as supportive care in the last year of life, and includes 'palliative care' as an holistic approach which may start earlier in the disease trajectory. The National Institute of Clinical Excellence (NICE

2011, updated 2017), asserts that end of life care is focused on the last twelve months of life. However, the Scottish Partnership for Palliative Care (2015) avoids a specific time line, identifying instead that end of life care is required when the patient has entered ‘the process of dying’. Differences in interpretation is further compounded by the acknowledgment that those with long-term care conditions (rather than cancer) may also have unmet palliative care needs (Seymour & Cassel 2017). Table 1 provides examples of terminology employed by palliative care providers in England and captures the end of life versus palliative tension within definitions.

Table 1: Definitions of palliative end of life and supportive care.

Term	Example definition	Example definition
Palliative care	Palliative care “improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” World Health Organization (WHO 2014)	“Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.”  National Council for Palliative Care (2015)
End of life care	“End of life care is support for people who are in the last months or years of their life. End of life care should help you to live as well as possible until you die, and to die with dignity. The people providing your care should ask you about your wishes and preferences, and take these into account as they work with you to plan your care.” NHS	“End of life care is “high-quality care for adults aged 18years and older with advanced, progressive, incurable conditions; adults who may die within 12 months; and those with life-threatening acute conditions. It also covers support for the families and carers of people in these groups.” National Institute for Clinical Excellence.” (NICE,

	Choices (2015).	2015)
Supportive Care	<p>“Supportive care helps the patient and their family to cope with their condition and treatment of it – from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximize the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment.” National Council for Palliative Care (2015).</p>	

In order to offer some consistency of nomenclature, and whilst acknowledging that definitions remain contested, this study will adopt the WHO (2014) definition as above. This definition encompasses the domains of pain management, family care, psychological and spiritual care, bereavement and quality of life and access to interventions and treatments to improve quality of life and symptom management for those with a life threatening illness, and recognises the palliative care needs of conditions other than cancer.

A further layer of meaning around palliative care lies in the specialist versus generalist delivery of palliative care distinction. General palliative care delivery may form part of the role of a range of clinical staff working within community and hospital settings. Specialist palliative care provides care within a specialist multidisciplinary care teams whose primary function is to provide specialist palliative services, as well provide advice and education to a range of settings including community, care home and hospices (National Council of Palliative Care 2015). Hospices are therefore providers of specialist palliative care services supporting the needs of people and their families with progressive life-limiting illnesses.

## **2.2 A background to hospice services in the UK**

The Economist Intelligence Unit (2015) declared that according to international comparisons, the UK has the 'best quality of death', (although with the caveat that even with this status, a number of factors including poor communication and planning can impact negatively on care). The positioning of the UK as a leader in palliative care delivery reflects in part the rise of the modern hospice movement within the UK (Borgstrom 2016). The hospice movement was specifically associated with terminal cancer care, but in recent years has begun to reach beyond cancer to a range of long-term conditions including dementia and heart failure. The hospice movement has spread worldwide (Howarth 2007) predominantly in Europe, Canada, Australia and USA, although there are debates around the applicability and desire for a hospice model within 'developing' international settings and range of cultural practices (Zaman et al 2016). The following provides a brief overview of palliative care and hospice care in the UK.

The history of hospice care is fully detailed by Noble & Winslow (2015) and Clark (2016) beginning with early medieval hospices run by religious orders and which provided care for the dying as well as shelter for pilgrims and travellers. Zaman et al. (2016) and Howarth (2007) cite that the early twentieth century saw a modernist shift toward a more secular delivery of care with an increased focus on pain relief and care of those identified as dying. A small number of religious institutions, such as St Joseph's hospice in London had begun to provide care for the dying in the early part of the twentieth century. In the mid twentieth century a small number of charities including the Marie Curie Memorial Foundation, began to provide homes for the care of those with terminal cancer (Noble & Winslow 2015). It was not until later in the twentieth century that the modern hospice emerged with the aim of supporting dying people, specifically those with terminal cancer (Clark 2008).

A number of pioneers, of whom Cicely Saunders is the most notable (Noble & Winslow 2015, Clark 2008), were influential in the development of the modern hospice. Cicely Saunders began to develop her ideas in the 1950s in her work

at St Joseph's hospice, London. Saunder's work focused on pain relief for those dying, particularly from terminal cancer (Seymour et al. 2005), an area of medical practice that had been somewhat neglected at that time (Clark 2016). The focus on pain management reflected some of the technological advances around pain relief (Ellis et al. 2015) and challenged practices around opiate use in terminal care. It is argued that her influence helped to establish palliative care as a medical speciality, addressing the 'side lining' of care of the dying (Holmes 2003, cited by Seymour 2012) described at the time by Eric Wilkes, as inadequate (Noble & Winslow 2015). Through her research, practice and observations, Saunders developed the holistic concept of 'total pain', aiming to address not just the physical aspects of pain management but also the emotional and spiritual needs of people facing the end of life. Saunders later founded St Christopher's hospice in London, often described as the first modern hospice and it was here that she was able to develop the concept of 'total pain' as an underlying philosophy central to palliative care practice (Seymour et al. 2005).

In 1964, Wilkes, a Sheffield General Practitioner, (along with other charismatic leaders) was influential in transporting the hospice ideal to other localities, with Sheffield being one of the first hospices established outside of London. Wilkes uniquely introduced a day care facility, providing a range of supportive interventions including medical care, physiotherapy, and occupational therapy, and support and respite to carers (Noble & Winslow 2015). Day care provision later formed part of hospice care delivery throughout the UK. The modern hospice model spread rapidly around the UK and internationally and reflected a number of social changes occurring at that time (Seymour 2012). Howarth (2007) similarly argues that her work complemented the work of other influential theorists emerging in the late twentieth century, including the work of Kubler-Ross' (1970) on bereavement and acceptance, as well as Glaser and Strauss's (1965) on dying awareness.

The proliferation of hospices through the latter part of the 20<sup>th</sup> century in the UK helped to establish palliative care as a recognised clinical speciality (Noble & Winslow 2015). Today, Hospice UK (originally Help the Hospices) coordinates

and regulates the independent and charitable status of the hospice care sector (Clark 2008). In 2010, there were an estimated 220 hospices, with 417 home care support teams, and 307 hospital support teams (Noble & Winslow 2015). Whilst hospices remain integral to health care, they are only part funded by the NHS, occupying an independent positioning which offers both a challenge to the medicalization of care (Howarth 2007, p.130) and an opportunity to integrate and develop with mainstream services (Clark 2008). Hospices exist as independent charitable providers of care however; as a medical and nursing speciality linking with the NHS care, national policy and professional standards apply and this alongside technological developments in symptom management have led some to suggest that palliative care has been subject to a process of remedicalization (Field 1996, cited in Seymour & Clark 1999). At the same time, questions of resource and focus continue to fuel debates around future models of palliative and hospice care. Debates particularly focus on generalist versus specialist provision (Seymour 2016) as well as the extension of palliative care for other life limiting illnesses including dementia. Contemporary debates around what is palliative care and who it should serve suggests that palliative care is an evolving concept.

The success of the hospice model has led some commentators to describe the proliferation of hospices as a 'movement', predominantly in Europe, Canada, Australia and USA (Zaman et al. 2016). Whilst this suggests that hospices present a 'success' in care delivery, there is however some critique. For example, the UK initially focused on care of the terminally ill cancer patient in contrast to the American context, in which hospice care held a broader focus (Seymour 2012). Hospices in the UK remain predominantly local, independent and charity based services. The Wilkes Report (cited in Clark 2008) expressed unease that expansion was ad hoc and outside of the NHS (Ellis et al, 2015). There has also been a growing perception of hospice care as white, middle class and Christian (Howarth 2007). Currently there is further criticism of the construction of the 'good death' within the historical evolution of hospice and palliative care as ethnocentric in perspective (Zaman et al. 2017).

Nevertheless, Borgstrom (2016) suggests that the success of the hospice movement in creating palliative care as a clinical speciality contributed to a growing recognition of palliative care needs within mainstream healthcare delivery. This culminated in the national End of Life Care Strategy (DH 2008) driven by the National End of life care programme with the aim of establishing best practice around palliative care delivery in mainstream services. This programme advocated a range of tools to support best practice including the gold standards framework, and the preferred priorities of care document (PPC). The End of Life Care Strategy (2008) progressed within a neoliberal context in which individualist principles of patient choice and autonomy and advance care planning predominated alongside an emphasis on quality and cost-effectiveness (Borgstrom (2016)). The notion of patient autonomy in some ways offers a challenge to medicalized processes, however, the use of standards and guidelines suggest a tension between patient choice versus a standardisation of the dying process.

The demographic shift toward longer life expectancy and associated co-morbidities has prompted a push for the recognition of long-term conditions such as heart failure, dementia, and frailty as requiring palliative care support, particularly in the context of older people with co morbidity (Van Vliet et al. 2015). However, given the potential impact on supply and demand, adoption of this wider approach has been tentative (Noble & Winslow 2015). Kellehear (2007, 2013) has called for the rendering of palliative care as a public and human rights issue (Zaman 2017). Initiatives, including 'Dying Matters' (<http://www.dyingmatters.org>), formed by a national coalition of providers has emerged with the aim of raising awareness and encouraging public engagement with advance care planning and supporting a range of activities including an annual Dying Matters week and the proliferation of so called 'death cafes'. Such approaches aim to encourage individual engagement with death planning in the effort to encourage 'better' dying for all (Borgstrom 2016). Choice and shared decision-making exist as a standard within this framework in which the individual is responsible for self-management of health, illness and death. Pollock & Wilson (2015) argues that choice and autonomy present as key measures of quality and equity (Pollock & Wilson 2015). The following

therefore presents a critical overview of choice and autonomy in the context of palliative care.

## **2.3 Autonomy and Choice in Palliative Care**

Autonomy in relation to patient centred care and advocacy is a key component of palliative and end-of-life care provision internationally. The following provides a critical discussion of autonomy and choice in end of life care, and was the basis of a paper published in 2013, (Wilson, F., Gott, M. & Ingleton, C. (2013). *Autonomy and choice in palliative care: time for a new model? Journal of Advanced Nursing* 70(5) 1020-1029.), and is reproduced (with permission from the Journal of Advanced Nursing and the University of Sheffield, Department of Research & Innovation (see Appendix 1)) as an abridged version (the original paper is provided in Appendix 2). The following section provides an updated policy context.

### **2.3.1 A review of choice and autonomy in the context of 2013-2016**

The published paper (Wilson et al. 2013, see Appendix 2) cites choice as a key objective within UK End of Life Care Strategy (DH 2008). Despite a number of shifts within the context of health and welfare provision, the emphasis on choice continues to permeate health policy, albeit with some caution. The global financial crash of 2008 prompted the adoption of an austerity model of neoliberal economics. In 2012, the coalition government introduced the new Health & Social Care Act (Great Britain 2012), which widened opportunities for local commissioning, and called for a revision of palliative care provision, with a particular focus on avoiding costly and potentially 'avoidable' hospital admissions (Wee 2016). Against this backdrop debates have ensued around generalist versus specialist palliative care (Seymour & Cassell 2017) and there is an increasing impetus toward recognising palliative care needs across a range of life limiting conditions (Noble & Winslow 2015). At the same time, Wee (2016) suggests that despite the success of the End of Life Care Strategy (DH

2008), in promoting palliative care as a cornerstone of care delivery, the demise of the Liverpool Care Pathway (reviewed in the Neuberger 2013 report: *“More Care, Less Pathway”*) has led to a more cautious approach toward future palliative care policy.

Patient choice was heavily promoted within the *“NHS end-of-life strategy for England: promoting high quality of care for all adults at end-of-life”* (DH, 2008). This document cites the word 'choice' forty five times in underlining the need for individual engagement in planning for end-of-life care decisions. The WHO (2011) document *“Palliative care for older people: better practices”* also championed 'choice' in end-of life care and place of death for older people. These policies were followed by the Health & Social Care Act (2012) and a climate of austerity economics. Although individual choice was foregrounded in the subsequent government commissioned report *“What’s important to me; a review of choice in end of life care”* (Choice in End of Life Care Partnership Board 2015), reports from an umbrella of key palliative care organisations were less sanguine. For example, the End of Life Care Coalition (2016) produced the report entitled *“On the brink”* in response to a perceived lack of progress to the 'Review of Choice' (DH 2015) recommendations. It is also revealing that the *“What’s important to me: a review of choice in end of life care”* (Choice in End of Life Care Partnership Board 2015) uses the term 'choice offer', rather than 'choice' and funding constraints are increasingly emphasised. The focus on the 'choice offer' is also evident in the *“One chance to get it right”* (Leadership Alliance for the Care of Dying People 2014) which exhorts professionals to enhance awareness of resources available to individuals as they make choices. The National Palliative and End of Life Care Partnership (2015 p.18) *“Ambitions for palliative and end of life care”* also offers a similar caveat around choice stating, “care professionals must be innovative in how to enable choice to be met, particularly within resource constraints”.

Whereas the End of Life Care Strategy (2008) promoted choice as a key feature of care, recent policy reflects a more nuanced construction of choice. The more recent government response to the 'Review of choice in end of life care', (DH 2016) is clear that “choice is not straightforward, and depends on informed,

sensitive, two-way conversations with dying people and their relatives and carers about what is important to them". This latest document cites commitment to *enabling*, rather than *providing* end of life care services and choice. However, as Borgstrom & Walter (2015) note, choice at end of life is often presented as part of a compassionate and integrated service, but is increasingly constrained by resourcing priorities, with the result that individuals are more concerned around accessing than choosing care. The construct of autonomy is therefore contested within the context of austerity economics. The following section based on an abridged version of the published article by Wilson et al. (2013) aims to provide an overview of autonomy as a central concept within palliative care and aims to explore the challenges and issues inherent in the practice of supporting autonomy at end of life.

### **2.3.2 Autonomy as a concept**

Choice and autonomy are regarded as essential components of palliative care delivery in the UK and internationally (Brogaard et al. 2012; Lau & O'Connor 2012). The following will trace the concept of autonomy within ethical frameworks before exploring the practice of autonomy in palliative care delivery.

Western understandings of autonomy focus on an individualised model of self-determination, with etymological origins in the Greek meaning 'self-rule' (Beauchamp & Childress 2001, Woods 2007, and Skilbeck 2005). This definition of autonomy links to the rise of individualism and enlightenment in Western culture. Gubrium & Holsten (2002, p.6) suggest that the age of enlightenment and the demise of absolute monarchy challenged the notion of the self as a subject and instead emphasises individual rights at a political and individual level. The concept of free will and choice only make sense within in the context of an autonomous individual.

The writings of John Stuart Mills (1806-1873) and Immanuel Kant (1724-1873) have been influential in shaping Western understandings of autonomy. Kantian autonomy embeds liberty and freedom within a moral framework, which asserts that individuals are due autonomy, but must also, respect the autonomy of

others. Kantian approaches describe autonomy as 'obligation based' (Beauchamp & Childress, 2001:348) and rest on an assumption that the individual is capable of rational reasoning to do what is morally right. Mill's approach recognises freewill and morality but assumes a negative logic, in that autonomy is freedom from interference by others, especially state agencies (Woods, 2007, p.84).

The philosophical writings of Mills and Kant inform two broad approaches to autonomy within utilitarian and neo liberal standpoints (Woods 2007 and Beauchamp & Childress (2001)). Utilitarian perspectives have a basis in Kantian logic and focus on rational balancing of happiness and pleasure and maximising benefits. This is not a purely hedonistic approach as the individual gains intrinsic value (pleasure) from undertaking a morally correct action. Beauchamp & Childress (2001) link such an approach to the notion of justice in which individual rights balance against wider societal responsibilities.

Neoliberal perspectives focus on self-determination and are perhaps the most dominant approach in Western healthcare ethics (Beauchamp & Childress 2001, and Randall & Downie 1999). Classical Liberalist notions of autonomy uphold the primacy of individual rights, both negative and positive. Negative rights assume that an individual can exercise the right not to do something (for example, refusal to undergo chemotherapy as part of an advance care plan), whilst positive rights refer to the right to receive goods or services (for example, free hospice care within a welfare system). Neoliberal positions tend to focus on the negative right and incorporate the idea that individual autonomy rests on non-interference from others. This logic is expressed in current debates supporting the individual's right to euthanasia and freedom from unwanted medical intervention, for example, the UK case of Tony Nicholson, (BBC 2012) and the US case of Terry Shiavo (Payne et al. 2008).

Interpretations of morality and ethics shape definitions of autonomy. Beauchamp & Childress (2001) provide a framework for exploring ethics in health practice; autonomy; justice; maleficence and beneficence. However, ethical decision-making requires a balance of interests and presents as fraught

with tensions. A dying person whose condition is deteriorating may be adamant in their wish for support at home, but the availability of services may place responsibility on relatives, which may be detrimental to their health. Despite Beauchamp & Childress's (2001) framework, the reconciliation of different tensions therefore remains challenging.

### **2.3.3 Challenges to autonomy**

Woods (2007) argues that individualised understandings of patient autonomy arose as a challenge to traditional and paternalistic models of medical practice. However, rather than a challenge to practice Woods (2007, p.78) argues that patient autonomy in palliative care actually complements a non-curative speciality in which a person-centred, holistic approach is desirable. Randall & Downie (1999), suggest that palliative care should offer a consensus approach to decision-making described as 'preference autonomy'. 'Preference autonomy' is described as medic (health professionals are defined as medics in this text) and patient interaction in which "the patient's informed choice as a self-determining and self-governing being is respected, as is the professional's choice of suitable treatments based on professional knowledge and skills" (Randall & Downie 1999, p. 212). What Woods (2007) and Randall & Downie (1999) appear to be proposing is a more open dialogue between health professionals and patients around informed choice. Whilst open dialogue might facilitate discussions on care, there are however constraints. Supporting autonomy requires that patients have willingness, knowledge and understanding to interpret choices, as well as the ability to make rational decisions. This presents a challenge to how choice is introduced and understood (Richards et al. 2013).

### **2.3.4 Tensions in supporting the 'informed patient'**

Informed consent is a contemporary feature of health care. For example, the NMC code of conduct (2008, p.3) states that "nurses must 'uphold people's

rights to be fully involved in decisions about their care”, whilst the updated NMC code (2015) exhorts nurses to ‘encourage and empower people to share decisions about their treatment and care’. Most nurses would recognise however, that giving information is not straightforward and presents the potential for adverse outcomes if poorly enacted. There are ethical dimensions to information giving which require a reflexive approach. For example, Gardiner et al. (2010) suggest that differences in lay and professional understandings around terminology can undermine informed consent. Beauchamp & Childress (2001, p.89) similarly suggest that how information is given can shape (mis) understandings. Options presented as probabilities or delivered using analogy to illustrate can also mislead and distort understandings (Oakley 2005). An added challenge is recognising when to initiate conversations around end-of-life, in a way that is timely and sensitive. Pollock & Wilson (2015) cite that skilled communication around end of life discussions are challenging for health professionals requiring high-level communication skills and consideration of the issues outlined below.

### **2.3.5 Choice and prognostication**

Gott et al. (2011), note that a key recommendation of the “*End-of-Life Care Strategy for England*” (2008) is that “death should become an explicit discussion point when patients are likely to die within 12 months”. Recognising if death is likely within a 12-month framework can be difficult for health professionals, particularly in non-cancer conditions such as chronic obstructive pulmonary disease, in which there is often a less clear journey of beginning and end. Opportunities to discuss care preferences are not always available or timely, particularly if health professionals are uncertain in how to address difficult conversations (Gott et al .2009). Recognizing the transition from curative to palliative care as well as knowing when to broach discussions is challenging, particularly in conditions with uncertain disease trajectory (Gardiner et al. 2011b)

The timing of discussions around choice and information giving requires ethical consideration. Overwhelming a patient with information at a point when they may be unwilling or unable to understand information is possibly an example of maleficence. Illness can threaten control and identity (Beauchamp & Childress 2001) and the need for information can fluctuate during shifts in health and wellbeing. A number of theories capture issues of adaptation and autonomy including Sprangers & Schwartz (1999) 'response shift' theory, which argues that changing circumstances can lead to a review of expectations and choices; what might seem untenable or conversely desirable is no longer following a period of transition. An example in palliative care is the well-documented shift around preference of place of death, the closer someone is to actually dying (Townsend et al.1990, Wood & Salter 2013). Shifts in preference resonate with theories of biographical disruption (Bury 2005 and Franks 2002) in which individuals regroup following a period of disjuncture. For example, Little et al. (1998) describe a transitional state of 'liminality' in which the individual enters a 'black box', with an uncertain outcome in terms of self-identity and management of illness. Those with palliative care needs, undergoing an embodied process of transition and loss of control or identity may experience psychological and physical inability to engage immediately with information and make decisions (Bradley 2011). Richards et al. (2013) also argue that despite an emphasis on 'open awareness' around prognosis, patients do not always desire this. Giving information is therefore sensitive and requires a balance of when and how to offer information in order to support individual autonomy around wishes to be informed and participate in care decisions. It also requires that health professionals, particularly nurses are sensitive in recognising and supporting transitional responses to information.

### **2.3.6 Hope and Autonomy**

Beauchamp & Childress (2001), Randall & Downie (1999) and Greener (2007) suggest that the emphasis on an individualised model of autonomy fails to give adequate recognition to the problem of how to facilitate information giving and choice whilst balancing the 'risk' of losing hope. The ethical imperative to 'do no

harm' in information giving may link to a desire on the part of health care professionals to sustain hope. Beauchamp & Childress (2001, p.286) state, "professional norms reflect the values of truthfulness, accuracy and empathy, along with the therapeutic value of hope for patients." Supporting hope as a coping mechanism however is problematic and Frank (2009) describes how 'false hope' can detract from opportunities for veracity in communications. A BBC Radio 4 broadcast (12<sup>th</sup> May 2008) illustrates this point in the narrative of the wife of the deceased Nick Clarke (a BBC journalist) in which she discusses how at the time, hope seemed so important but actually reduced opportunities for honest conversations later acknowledged as important.

The Mental Capacity Act (Great Britain 2005) requires an assessment of individual competence when making care decisions. In the context of palliative care, competence and mental capacity can be both intermittent and deteriorating as disease progresses. For this reason, there is an increasing emphasis on advance care directives or care planning using documentation such as the '*Preferred Priorities of Care*' (PPC) (DH 2008) reflecting the work of Kellehear (1999) in calling for a public health approach to palliative care. UK initiatives around a palliative public health include the emergence of Dying Matters, formed by the National Council for Palliative Care (NCPC), which fosters a wider understanding through death cafes and other public health events. However, serious illness can render care decisions onerous at end-of-life, with tensions between wanting control and wanting to be cared for (Seymour 2004). Indeed, Greener (2007) suggests patients may prefer that health professionals provide guidance, resonating with Seymour's findings (2004) that older people regard trust and on-going dialogue as essential in delivering end-of-life care, rather than a formal stand-alone plan. These considerations may account for the low use of advance care planning initiatives in the UK (Harris 2011) and USA (Frank & Anselmi 2011), despite the recommendations of the UK National End of Life Care Programme (2008) and "*What's important to me: a review of choice in end of life care*" (The choice in end of life programme board, 2015).

### 2.3.7 Autonomy and the nursing role

Battin (1994) suggests that as deterioration occurs, patients may be less concerned with wider decisions around care such as place of care, and more concerned with immediate comfort, and physical relief of pain. At this point patient autonomy is vulnerable but offset by attending to those personal aspects of care, which can be vitally important to an individual in retaining a sense of control and dignity. Montgomery & Little (2011) describe such an approach as enabling 'patient agency'. This concept, based on Giddens's work (Montgomery & Little, 2011, p.3) defines patient agency as engagement in care but also as "recipients of others agency" (for example, by being affected by others' actions during the course of treatment). Bradley et al. (2011) cite that agency and patient centred care can maintain self-esteem in the more minor social interactions around choice such as what to disclose, eat, where to sit, and so forth. Whilst seemingly minor, these are important psychosocial factors in maximising a sense of control. Montgomery & Little (2011) also capture narrative accounts in which patient agency is subtly undermined by care plans which are not fully understood, for example a patient accepts a naso-gastric tube which is uncomfortable, and asks whether it can be removed and is unaware that its insertion was precautionary and not a necessary part of care. The Francis Report (Neuberger 2013) explored poor practice in a UK hospital trust and supports the contention that attending to not only the 'big' decisions but to the smaller aspects of care affords patient agency and autonomy in everyday care. In terms of 'bigger' decisions around autonomy, Randall & Downie (1999, p.35) argue that the primary focus of medical practice is to act within the patient's best interest and this may lead to decisions contrary to patient autonomy (for example ceasing chemotherapy which is no longer therapeutic despite patient demand). Randall & Downie (1999, p.75) legitimise this approach arguing that health professionals are best placed to assess care options given professional knowledge. However, the review of the Liverpool Care Pathway (Neuberger 2013) suggests that in practice, patient autonomy can be overruled or ignored.

It is debatable whether nurses are empowered to challenge or contribute to ethical decisions around care (Hyland 2002, Schwartz 2002 and Frank 2009). In terms of supporting information giving, key texts such as Randall & Downie (1999) and Beauchamp & Childress (2001) give very little recognition to the nursing role in decision-making and information giving. Hyland (2002) argues that nurses are often involved as intermediaries to support and explain information but rarely lead key interactions. The nurse role in supporting patient autonomy and choice may be impeded by a medical hierarchy in which nurses are expected to support decisions, but are not be expected to engage in decision-making processes. As a result, Frank (2009) suggests nurses themselves may not recognise their role in supporting patient autonomy and may not be equipped or empowered to participate in discussions around choice and care. Dixon et al. (2015) identify that professionals are unclear of their role around advance care planning. On the one hand nurses are called to 'encourage and empower people to share decisions about their treatment and care,' whilst at the same time 'respect the level to which people receiving care want to be involved in decisions about their own health, wellbeing and care' (NMC 2015). There are also criticisms of the concept of nurses as 'patient advocates' including concerns around paternalism, lack of empowerment, little education around the concepts of advocacy and autonomy, as well as the potential for interprofessional discord as the concept of 'nurse advocate' sets nurses apart from the team (Hyland 2002 and Schwartz 2002).

### **2.3.8 Autonomy and Power**

Despite the assertion in the "*End of Life Care Strategy*" that a key objective is to "ensure that people's individual needs, priorities and preferences for end-of-life care are identified, documented, reviewed, respected and acted upon wherever possible" (DH 2008, p.18) the autonomous patient may be thwarted by social context and the inability to exercise power. Murphy (1994, cited in Sheldon & Thomson, 1998) critically explores the discourse in interactions between health professionals and patients using the theories of Foucault and Habermas. Murphy (1998) suggests that health professional interactions as 'expert' and

'informed' professional discourse can dominate the patient's voice, constraining opportunities for choice.

Economic and structural factors also impinge on patient autonomy, particularly in a health care market that is limited and rationed. Cohen (2011) discusses how the body and caring have become a site of labour relations and that given the current 'austerity' measures and emphasis on efficiency savings, this applies even in the context of palliative care. Randall & Downie (1999) suggest that professional decision-making based on guidelines for best clinical practice reduce the possibility of bias or conflict. However, Public Health England (2013) suggests that home and social care costs are less than hospital costs in the last year of life. Home is constructed as the best place of care within this context (Pollock 2015) and suggests that clinical decision-making and informed choice can be influenced by cost considerations (De Vries et al. 2012 and Eagle & De Vries, 2005). Greener (2007) therefore questions the whole notion of an expert, self-deterministic patient given the constraints in service provision. Individuals who struggle to access services or whose choices are bound by professional definitions of patient 'best interest' may fail to make decisions, and may demonstrate a 'learned helplessness' with regard to care decisions (Battin 1994). Indeed, Battin (1994) argues that such passivity can contribute to the failure to engage in future care plans so that often it is sudden crisis or deterioration that triggers treatment options, rather than patient wishes.

A public health agenda advocating decision-making prior to crisis may be a positive intervention. However, this requires a building of relationships and trust not just in a health context, but also in a 'network of trust' (Giddens 1999, cited in Murphy 1998). Patient and professional interactions are multiple, and within the UK typically take place within a large NHS system and across third sector and other providers. Whilst palliative care may involve fewer and more intimate relationships between clinicians and patients, Hardy's work (2011) suggests that patients nevertheless receive care from a wide range of health and social care professionals that can be confusing and contradictory. Seymour et al. (2004) and Broome et al. (2012) note that trust is crucial in the context of supporting older people and their carers as they negotiate services within social

and health care systems. Where there are a number of people involved in providing care, then developing trusting relationships is more challenging and has the potential to undermine discussion around care preferences. The work of Broome et al. (2012) suggests that a decision ecology framework recognises the importance of relationships and trust in choice, and enables a reconceptualising of autonomy that takes into account patient and carer experience.

### **2.3.9 Challenges to individual autonomy**

Woods (2007) argues for a communitarian model of autonomy, which derives from societal understandings around shared values and relationships. Such an approach repudiates the emphasis on neo liberal and utilitarian individualised approaches. Zelderloo (2009) argues that the reality of people's lives is one of interdependency. Woods (2007), and Broom (2012) similarly argue for recognition of the relational aspects of autonomy to include a contextualised and community focused understanding. Broome (2012) also argues that acknowledgement of the wider social systems that operate around individuals may enhance conversations by honestly acknowledging the uncertain nature of patient choice and limitations of care services. 'Choice' is therefore informed not only by the principles of maleficence, justice and beneficence, but also by the wider cultural and social networks in which people exist and the discourses available to patients, families and health professionals.

Factors shaping access to care include gender, ethnicity and age. Women tend to be carers in the family context, and therefore it is often who women who tend to the dying (Biggs 1998, Williams et al. 2017). As women tend to live longer and alone, they may in turn find their dying experiences are reliant on state and institutional resources, rather than care in their own home. Venkatasalu (2011) in a study involving South Asian understandings around end of life, captures that gender and ethnicity intersect and whilst family orientated approaches to decision-making are preferred in the South Asian community, women's autonomy is dependent on their position within the family. Dialogues around

choice and care should therefore take into account the gendered nature of dying and care with support in place to ensure access to services and support.

A number of studies draw attention to the impact of cultural understanding around hospice and palliative care on access to services. For example, Worth et al. (2005) in a UK study of South Asian Sikh and Muslim participants argue that due to cultural misunderstandings and language some ethnic groups experience barriers to receiving care. Venkatasalu (2011) similarly explores how cultural understandings shaped decision-making reflecting the work of Bito et al. (2007), which found that Japanese approaches to decision-making focus on family orientated decision-making rather than an individualised model of autonomy. In the context of New Zealand, Bellamy & Gott (2013) also found that indigenous groups prefer a collective and family orientated approach to decision-making. Lau & O'Conner (2012) underline that cultural (mis)understandings between health professionals and different ethnic groups undermined access to services. These studies indicate that an individualised model of care may not be culturally acceptable for some ethnic groups. Nurses working with a multicultural demographic should acknowledge the need to engage in culturally sensitive practice, particularly in palliative care where middle class, white and Christian values tend to predominate (Howarth 2007). Failure to understand and respect wider belief systems has the potential to impact negatively on the care experience (Frey 2013).

Issues of age shapes access to care, and Gomes et al. (2011), exploring local preferences and place of death in the UK, highlight that the numbers of older people dying in hospices is low, but numbers dying in the hospital setting are high, despite hospice being a preferred place of care by older people. Thomas (2004) suggests that factors, such as complexity of disease, social support, and service provision may shape the discrepancy between choice and outcome in older people and Gardiner et al. (2011a) argue that older people's palliative care needs can be overlooked, particularly in the acute sector. In the context of ageing an ageing population, it is important that a model of autonomy addresses issues of equality and equity in care provision for older people.

Assumptions around caring contexts may constrain patient autonomy and choice. Biggs (1998) suggest that individualised models of autonomy fail to recognise the social relations surrounding individuals. Lavoie et al. (2011) suggests demographic shifts and shifting networks impact on carer availability and willingness of carers to care and by default shape autonomy around care decisions. Broom & Kirby (2012) similarly identified that older participants in their study were aware of being a burden; particularly as individualised economic structures can erode traditional family networks and undermine traditional family care giving relationships. A common assumption is that family carers provide informal care, however Broom & Kirby (2012) argue for the need to recognise wider social support networks and potential for choice and autonomy. Social networks can include neighbours, friends and informal support. Recognition of the wider social context surrounding individuals is therefore important in understanding the impact on choice and decisions on individuals and those who care for them.

## **2.4 Relational autonomy**

An understanding of autonomy that moves away from a purely individualised focus and offers the potential to explore a broader conception of how autonomy, may encompass both interpersonal dimensions, as well as wider factors, may support greater resilience in coping with end of life. Broome et al. (2012) offer an ecology framework, which attempts to look at both individual and meso level elements of choice and autonomy and describe such an encompassing approach as a 'decision ecology'. This concept explores decision-making in the care of older people and foregrounds notions of awareness of the whole individual, particularly their narratives, social capital and relationships, as well as service provision. A decision ecology model also recognises the importance of building trust between older people and the care agencies around them. This includes a candid acknowledgement of the realities and risks, and availability of services in discussions around care. The ecology model emerged in the context of older people and social care; nevertheless, there is the possibility of resonance around autonomy and decision-making within palliative care.

How nurses engage in decision ecology depends on the relationships nurses develop with those in the interprofessional team and patients in their care. Hyland (2002) and Frank (2011) suggest that nurses must aim to interact as equal partners as part of an integrated team and should envisage that they are able to support patient choice. Richards et al. (2013) identify that whilst medics may initiate end-of-life discussions, nurses deliver care, and therefore an interprofessional approach is more relevant in exploring patient and family needs around choice and care. Key areas of focus to support a decision ecology in palliative care need to provide a framework for recognising transitions to palliative care and how to initiate discussions around care which are timely, sensitive to transitions, and flexible. It would seem that choice and autonomy is supported by relationships which engender a trust within the care systems as well as personal trust (Seymour et al. 2004), and such relationships must engage with the social context and resources available to the individual. Richards et al. (2013) suggest that nurses must contribute to wider discussions around care and practice in a way that considers broader aspects of relational autonomy. An integrated approach may be more effective in considering the 'wider social context, including individual narratives, care networks and trust' (Broome et al. 2012).

This chapter has provided a background to hospice care and current end of life care policy in the UK in which choice and decision-making present as fundamental concepts in care delivery. The following chapter will provide a literature review that explores factors around decisions to access hospice services.

# Chapter 3: Review of the literature

## 3.1 Introduction

This literature review explores the factors that enable or constrain choice in accessing hospice services. The review was systematically conducted in two distinct phases, with **Phase One** presenting an initial integrative review conducted at the beginning of this study in January 2010, and **Phase Two** providing an update of the literature occurring over the lifespan of the study. (March 2010-2016). **Phase One** was important in shaping the study aims around access to hospice care. This initial work has since contributed to the expanding knowledge base around choice and decision-making in hospice care, and was successfully published (Wilson, F., Gott, M. & Ingleton, C. (2011). Perceived risks around choice and decision-making at end-of-life: A literature review. *Palliative medicine* 27(1) 38-53 impact factor 3.685) and cited by others, for example, in a Hospice UK report 'Supporting Family Carers' (Payne et al. 2013). Appendix 3 provides a copy of the published article. The review also informed a poster presentation at the 10<sup>th</sup> Palliative Care Conference (2014, see Appendix 4). The following describes the search process for Phase One and Phase Two and the findings from both phases are combined in a thematic analysis presented in section three.

## 3.2 The contested literature review

A social constructivist grounded theory approach acknowledges that the literature review is 'disputed' (Charmaz 2006; Gibson & Hartman 2014). Classic grounded theory asserts that researchers should remain as *tabula rasa*, and should avoid reviewing the literature until *after* completing analysis (Gibson & Hartman 2014, p. 203). A number of constructivist researchers including Charmaz (2006), Dunne (2011) and Mcghee, et al. (2007) have challenged this approach for a number of reasons. Firstly, whilst acknowledging that grounded

theory is inductive, the constant comparative method indicates an iterative process of induction and deduction, of which the literature review is a part. Secondly, social constructivist grounded theory (SCGT) presents a shift away from positivist approaches of researcher objectivism and instead acknowledges the role of the researcher in the research process. Dunne (2011) argues for a 'middle' ground approach described as a 'defensible' position in which reflexivity informs the research process from literature review to interpretation. This in many ways fits with the approach advocated by Charmaz of 'theoretical agnosticism' in which the literature is acknowledged reflexively (Gibson & Hartman 2014). Thirdly, as suggested by Charmaz (2006) the timing of the literature review at an initial early stage enables clarification of ideas, prepares for the requirements of the ethics committee and demonstrates an understanding of the research context. It is unlikely that access would have been permitted to a palliative care setting had I, the researcher, *not* had prior knowledge of the research context.

This study occurred over a number of years and a second review of the literature emerging from 2010 onwards was conducted following analysis of the study findings, in order to further contextualise the findings and discussion within the current evidence base. The review of the literature focused on choice and decision-making within the UK context and primarily within the hospice setting. The following section presents an integrative review of the literature and will detail the search process for phase one and phase two respectively.

### **3.3 Phase One: January 1998- February 2010**

The following integrative review explores the factors shaping choice and decision-making in accessing hospice care. Whitemore & Knafl (2005) describe an integrative review as one that considers a range of primary research methodology in order to extend the evidence base. Enacting choice and decision-making captures a balancing of uncertainty and risk, shaped by a complexity of social norms, culture, emotion, trust, and knowledge (Zinn & Taylor-Gooby, 2006, p.64). The phase one review of the literature therefore

aimed to explore how perceptions of risk influence how people access hospice care. However, an initial scoping of the literature indicated implicit rather than explicit assumptions regarding choice and risk within palliative care literature. The review therefore focused on issues of choice and decision-making in how individuals access hospice care. The review identifies a number of important themes shaping access to hospice services.

The Economist Intelligence Unit (2010) identifies the heterogeneous nature of international service provision around palliative care, particularly regarding funding and hospice availability. Phase one therefore focused on the UK context only. Between January and February 2010 the following search terms: decision\*; risk\*; hospice OR palliative OR “end of life care” were applied to the databases: Medline (EBSCO); PsycINFO; ASSIA (Applied Social Sciences Index and Abstracts); British Nursing Index; High Wire Press; CINAHL (Current Index to Nursing and Allied Health Literature). The search excluded articles focussing on issues of paediatric, euthanasia or assisted suicide, health insurance, or end of life care in contexts such as critical or acute care. 242 papers (including two articles from the ‘grey’ literature retrieved from palliative care websites) were explored for relevance using the following criteria: adult focus; hospice or palliative care context; and data from 1998-2010. The literature was organised using the bibliographic database Refworks. Table 2 presents an overview of databases and search terms.

Table 2: Databases and search terms 1998-2010.

Database	Search terms	Results	Number retained for exploration
Highwire Press (1998-2010)	Decision* Risk* Hospice OR palliative care	227	42
Medline Ebsco 2000-2010	Palliative care AND risk* AND decision	64	64

CINAHL 1998-2010	Decision* AND choice AND palliative care OR "end-of-life" OR hospice	138	40
High Wire Press	Decision* AND hospice AND palliative care	227	16
British Nursing Index	Decision* Or concern* AND hospice	165	63
ASSIA	Anxiety* OR risk* OR decision* AND hospice	6	3
PsycINFO	Anxiety OR risk OR decision AND hospice	37	12

The review identified 25 papers, including qualitative studies as well as studies involving survey data. Figure 1 provides a flow chart of the search process.

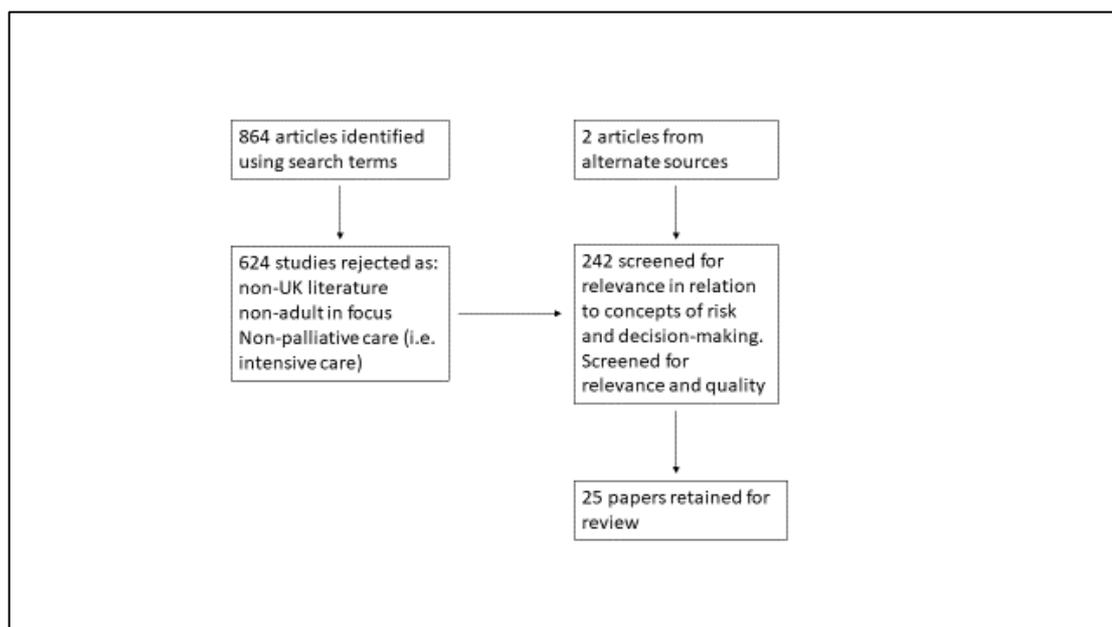


Figure 1: Flow chart of search strategy: phase one

Hawker et al. (2002) advocate that quality assessment should enable the appraisal of a range of qualitative and quantitative evidence (see Appendix 5 for Hawker et al. 2002, 'Framework for Assessment'). Hawker et al. (2002) advocate appraisal of the evidence using a range of tools to review aims; clarity of method; sampling; analysis; discussion of ethics; findings; transferability and implications or usefulness; discussion of limitations and ethical considerations.

All papers were explored using thematic analysis and argumentation (a process of identifying pivotal terms such as 'however, therefore' to ascertain key arguments as a means of critical reading (Hart 1998) as well as looking for repeated themes or patterns. Table 3 provides details of selected papers. The themes capture a number of factors that influence decision-making in end of life care both from the perspective of service providers and service users.

### **3.4 Phase Two: March 2010-September 2016**

The study spans 2010 to 2016 during which time a global economic recession and the consequent adoption by the UK coalition government of an economic 'austerity' model as well as the introduction of the Health & Social Care Act (2012) have shaped recent service provision in health and social care. The aim of the phase two review was to firstly help to contextualise the discussion of findings within an updated literature review, and secondly to ensure that the themes from phase one remained current given the changing policy context. A systematic approach was undertaken in reviewing the search of Phase One. As stated earlier, 'risks' around choice were implicit rather than explicit and therefore "risk" was not utilised as a search term in phase two. Phase One excluded non-UK literature. However, there is an increasing international body of work, which is highly pertinent to questions around choice and hospice care. Some of this is emerging within the Australian and New Zealand context, with a small number of researchers (including, for example Professor Gott) working across the UK and New Zealand contexts. Material that explored choice and decisions around transition to hospice care, in the context of Australia and New Zealand, was included in Phase Two, but only if factors less relevant to the UK context (issues of insurance, euthanasia or particular populations) were not the key focus.

Throughout the period of the study (2010-2016) weekly RSS (Really Simple Syndication) feeds were established via an EBSCO host alert using the terms 'hospice' AND 'decision\*' OR 'Choice'. Between November and December 2016 138 articles were retrieved from CINAHL and Medline EBSCO using the terms Choice AND decision\* AND Palliative OR "end of life" OR 'hospice'. The RSS feeds and search combined provided a total 253 papers. Articles retained were examined for relevance to the study aims (adult end of life or palliative care in the context of decision-making, choice and hospice care) at level of title and abstract. Articles excluded generally focused on paediatric or critical care settings or explored broader topics around palliative care and choice (such as bereavement and euthanasia) or literatures associated with training, and

decisions specific to cancer treatment. The search process identified 38 papers (see Table 4 'Phase Two: summary of selected papers') which were examined using the quality appraisal process as in phase one. A process of looking for key patterns and trends formed a process of thematic analysis as illustrated in the 'Thematic Matrix' (see Appendix 6). Figure 2 provides a flow chart of the search process for Phase Two.

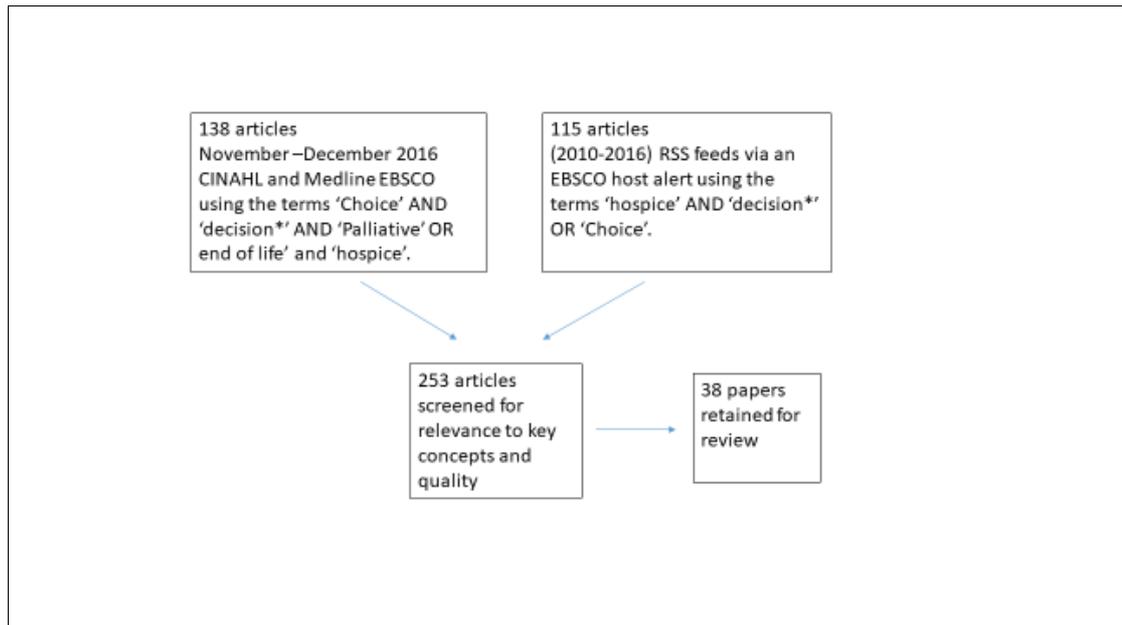


Figure 2: Flow chart of Phase Two literature search

### 3.5 Key themes from Phase One and Phase Two

The findings of both phases indicate that decisions or choice appear to be constrained by a range of factors including management of resources (including both personal resources for example, carer availability and service provision), access to services, timeliness of information, and issues around service user and provider understandings and expectations of place of care. The evidence from phase two reflects a growing policy focus on home care. The following presents the literature from January 1998 to September 2016. The key themes of the literature from Phase One and Phase Two are as follows:

- Patient and Carer Perceptions of place of care;
- Caregiver support;
- Funding and resources;

- Inequalities and inequity in accessing hospice services;
- Timeliness of information giving;
- Dissonance in service providers and patient and carer understandings of services.

### **3.5.1 Patient and Carer Perceptions of place of care**

The literature, particularly that emerging between 2010-2016 emphasises patient choice around place of care. Recent policy documents such as *“National Ambitions for palliative and end of life care 2015-2020”* (National End of Life Care Partnership 2015) and *“Our commitment to you”* (DH 2016) infer the potential for financial savings as well as opportunities for a ‘wider reach’ (with regard to numbers of patients and range of conditions) in providing home care. Given that home care is emphasised as a ‘choice offer’ (National End of Life Care Partnership 2015), it is interesting to explore what is understood by ‘place’ in the context of palliative care and how this may impact on patient and carer decisions to use hospice services.

Rigby et al. (2010) in a review of the literature regarding older people’s perceptions of the care environment suggest that a sense of ‘homeliness’ is highly valued. Cotterall (2008) in a small qualitative study exploring perceptions of care in those with a life limiting illness similarly identified maintenance of independence and home care as important, so that initial responses to hospice referral were emotional. Gott et al. (2004) in a study exploring older people’s views on end-of-life care also captures how meanings of ‘home’ include familiarity, security and loved ones, however, both studies caution that medicalised home care can threaten notions of ‘home’ and independence. It would seem that ‘home’ as a concept engenders notions of independence, and self-identity. However, work by Milligan et al. (2016), involving fifty-nine bereaved carers with experience of providing care at least two weeks before death, argues that ‘home’ is a contested concept. This work explored the concept of ‘home’ in recording place of death and found this was not necessarily the usual place of residence, with carers either moving in to

relatives' homes or vice versa, and unfamiliar 'home' environments challenged notions of familiarity and security and family dynamics.

A number of studies suggest individuals often consider the needs of those close to them when considering care decisions, particularly place of care. Sutton & Coast (2012) conducted a qualitative study of people aged over 65 years who were receiving care from the general practitioner (GP), or living in residential care or receiving palliative care. This study identified that older people were less concerned around issues of autonomy and more concerned not to be a burden to others. Work by Gott et al. (2004 ) similarly found that older people were keenly aware of the potential 'burden' that home care might place on family carers. This study echoes Lawton's (1998) ethnographic study exploring the concept of the 'unbounded body' and sequestration to hospice care in which people identified carer burden as a key consideration in the transfer to hospice.

Despite the emphasis on home as a preferred place of death, Woods & Salter (2013) assert that 60% of people currently die in hospital and with higher financial costs to services. Service providers working within financial constraints may regard hospital death as a negative outcome however; patients and carer may have different perceptions (Gott 2014). For example, Robinson et al. (2015) in a New Zealand based study involving fourteen palliative care patients admitted to a general hospital found that hospital offered a sense of safety and relief for the family as well as providing a sense of improvement in wellbeing. In the UK context, Hunt et al. (2014) explored data from the UK VOICES survey (involving a census of all deaths between 2009 and 2010 in two English health districts) and similarly identified that some carers felt that despite the outcome, hospital care was the best option at that time. These findings suggest that perceptions of best place of care or death are likely to be complex and layered.

Preferred place of care appears to differ between cultures. For example, McQuillan & Van Doorslaer (2007) explored the views of Irish Travellers and palliative care staff in a phenomenological study that explored both Traveller and professional care staff views of place of care preference. Care at home

was preferred but dying at home was not, and required either the destruction or spiritual cleansing of the home. Hospice care was valued but was associated with death and therefore inauspicious. A similar picture is provided by Seymour et al. (2007) in a UK study comparing perceptions of end of life between White (n=77) and Chinese elders (n=92). White participants preferred home as a place of care and death, but with concerns about caregiver burden. Hospice care was associated with dying and the 'good death', but participants regarded hospital care as impersonal. In contrast, whilst Chinese elders held similar concerns with regard to burdening carers, hospice care was constructed as 'inauspicious' and hospital care was seen as a place of hope. Dying at home was also inauspicious and to be avoided. These studies suggest that cultural considerations shape preferences around hospice use. Place of care therefore appears to be shaped by a number of factors including cultural preference, avoidance of being a burden, perceptions of place and impact on identity and independence. Such findings contest the current policy emphasis on home care and indicate that some individuals may consider hospice or hospital care as an appropriate option as they face end of life.

### **3.5.2 Caregiver support**

The term 'carer' is open to interpretation. Payne & Morbey (2013) recognise 'informal' caregivers as family members but also acknowledge the informal networks of friends and neighbours. A definition of 'carer' based on work by Thomas et al. (2001) and subsequently adopted by UK NICE guidance (2004, p.155) identifies carers as "carers who may or may not be family members, are lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management". This latter definition of family includes 'those that are self-defined or patient-defined as significant' and will be the definition adopted within this study.

Caregiver support appears to be an important factor in shaping service use. Thomas, et al. (2004) conducted qualitative interviews with forty-one terminally ill cancer patients and eighteen informal carers in the North West of England, UK. Home was the preferred place of death/care; however, the perceived

ability and availability of family caregivers tempered this preference. Similar findings by Gage et al. (2015) in a comparison of outcomes around place of death explored patient referrals (n=688) to a community rapid response service linked to a UK hospice found that individuals are less likely to die in their preferred place of care if family carers are unavailable. A literature review of family carer needs (Morris et al. 2015) also captures that the availability of carer resources as well as understandings around services constrains options and therefore choice. Importantly, given the context of an ageing population, Morris et al. (2015) suggest that gaps in service provision can be particularly negative for older carers who may themselves have care needs.

A number of studies explore the involvement of family carer in care decisions. Broom & Kirby (2013) in the Australian context used a qualitative approach to explore the experiences of hospice care referral with hospice inpatients and suggest that in practice, acceptance of hospice care is a relational decision shaped by family dynamics and carer support, rather than simply individual choice. However, in another Australian study involving interviews with medics, Kirby et al. (2014a, 2014b) suggest that clinical conversations around hospice referral perceive informal carers either as resources to aid decision-making or obstacles. Similar processes appear to operate in the UK context. Addington-Hall & O'Callaghan (2009) in a comparison of care provided in the last three months of life between hospital and hospice, found that family carers evaluated hospice care positively with regard to involvement in a decision-making process, compared to hospital care. More starkly, Lawson et al. (2013) in a qualitative study exploring the transition of older adults in the last year of life to a hospital setting, highlighted the frustrations of family carers whose input was often overlooked by professionals, despite their considerable role in caring. Seamark (2014) identified similar findings in a qualitative study involving fifty-nine bereaved family carers who also reported carer frustrations around opportunities for involvement in caregiving decisions.

Grande et al. (2009) provide a commentary arguing for greater understandings around carers' needs. Supporting carers however, can be difficult when carers themselves do not identify as either being carers, or having needs. For

example, in a literature review exploring the bereavement needs of family carers, Agnew et al. (2010) identify that the National Institute for Clinical Excellence (2004) recommends self-referral as the appropriate route for receiving bereavement support. However, self-referral requires insight in to one's needs as well services available. Ewing & Grande, (2013) developed the Carers Assessment of Needs Tool (CSNAT) to help identify carer needs, and caregiver burden. Carduff et al. (2016) utilised the CSNAT tool in a study involving twenty-five family carers identified via a UK general practice care register. Carduff et al. (2016) identified that twenty of the carers had unrecognised support needs. Harrop et al. (2014) also found carers had unmet needs through a series of focus groups with carers and staff in the hospice setting which revealed a lack of carer self-awareness, carers' limited knowledge of available support, and reduced opportunities for support or involvement in care decisions. Both Carduff et al. (2016) and Harrop et al. (2014) concur that the rise in palliative care needs requires a public health approach to raise awareness and provide support to those involved in a caring role.

### **3.5.3 Funding and resources**

The literature suggests that the use of hospice services requires consideration around cost effectiveness, efficiency and timely and appropriate service use. As a result, there is an increasing interest in developing admissions tools, which offer the potential to prioritise care needs. Fergus et al. (2008) evaluated a range of hospice admission tools and found that reliability and inter-rater reliability of assessment tools was poor and compromised by lack of clear admission details, clinical autonomy and the subjective understandings of admitting staff. Lawton (1998) suggests that patient referral to hospice care occurs when bodily disintegration is unmanageable in the community context. Access to specialist services may therefore focus on physical crisis, and hospice services may prioritise 'difficult' cases over carefully considered patient preferences in order to manage bed availability, rather than access being a 'considered choice'.

Concerns over access to and funding of specialist palliative care provision has driven the agenda toward improving quality of care in care settings including hospices and in conditions other than cancer (for example, NHS England, (2014) "*Actions for End of Life Care: 2014-16*"). This may require cultural change, however, (Kennedy et al. 2009), in an exploration of key stakeholders (managerial and organisational) perspectives of the NHS 'end-of-life care' programme highlighted organisational resistance to introducing change, as well as inequities between different localities and issues of sustainability of programmes of care. Similar concerns regarding equity of access appear more recently in the Department of Health document "*Our commitment to you at end of life*" (2015, p.11) which aims to 'end variation in geography, age, diagnosis, background or means'. However, the *Health & Social Care Act* (Great Britain 2012) presents a reorganisation of health and social care, particularly regarding an emphasis on the local commissioning of services including end of life care. Concerns therefore remain regarding geographical variability and impact on equity of access to services (Dixon et al. 2015).

Morris, (2012) provides a commentary that suggests that older people are less likely to access palliative care. There is an argument that long-term care may be an appropriate location of care for older people (House of Commons Health Committee Parliamentary Review 2015). Such decisions however, may be at odds with the preferences of older people and carers. For example, Thomas et al. (2004) in a qualitative study of palliative patients and preference for place of death found that older people regarded nursing home care as a last resort. Enes et al. (2004) explored responses to discussions around transfer to nursing home in a retrospective study of exploring the case notes of forty patients. This study found that responses varied from acceptance to distress, particularly as the mean length of stay following transfer to a nursing home prior to death was 8 weeks. Disparity in terms of perceptions of who should access hospice care, particularly with regard to older people with dementia has implications for the theme of 'inequality and access' discussed below.

### **3.5.4 Inequalities and inequity in accessing hospice services**

A number of studies suggest that issues of social deprivation, type of condition (particularly non-cancer), age, ethnicity and gender shape access to hospice services. Kessler et al. (2008) explored inequalities in accessing health services at end-of-life using data derived from the Public Health Mortality database. Using the standard occupational classification<sup>1</sup> the study asserts that carers from social class IV and V are more likely to receive support from extended family and individuals and are less likely to die in a hospice. Interviews with carers indicated that those in social class IV and V were passive in requiring information and when a crisis required access to either hospital or hospice care this was described as 'a battle' causing anxiety and undermining control and choice. Campbell et al. (2010) explored UK census data to compare two distinct areas of Manchester and similarly identified fewer hospice referral rates, despite a higher rate of cancer, in the area classified as having higher levels of deprivation. Campbell et al. (2010) however, acknowledge that whilst social deprivation is an indicator of hospice user, it is not clear which aspects of social deprivation shape such disparities.

Historically, hospices have provided end-of-life care for cancer patients (Addington-Hall & Hunt, 2012) however, Dixon et al. (2015) in a review of academic literature and data from the 2013 national survey of bereaved people in England, identify that a range of non-cancer conditions account for the majority of deaths yet few receive palliative care support. This is despite a growing shift toward expanding the remit of palliative care to include non-cancer diagnoses (for example, long term conditions, such as dementia, neurological conditions, chronic pulmonary obstructive disease (COPD) and heart failure). Mcilfattrick (2007) through a series of focus groups identified that health care providers and patients found the term palliative care problematic to define, particularly with regard to non-malignant conditions, and attributes this to uncertainty around prognosis and disease trajectory.

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<sup>1</sup> Standard Occupational classification: I -professional occupations; I managerial and technical occupations; III- skilled occupations; non-manual skilled, manual skilled; IV- semi-skilled occupations and V -unskilled occupations.

Gott et al. (2008) suggest that older people may experience barriers in accessing hospice care. Gardiner et al. (2011a) conducted four focus groups with professionals working in either General Practice, the acute hospital or the hospice setting, and suggest that a lack of resources as well as perceptions of need, present as barriers to older people in accessing palliative care. Dementia would appear to add a further obstacle. For example, Ryan et al. (2013) in exploring indicators of palliative care need in two UK hospitals identify that older people (>65 years) with dementia displayed higher levels of physical burden but were less likely to be referred to palliative services. Similarly, Perrels et al. (2014) explore transitions for older people >75 years in the last three months of life. This UK based longitudinal study revealed that older people with higher levels of cognitive impairment and aged over 85 years were more likely to move from their usual place of residence in the last 3 months before death, generally to a hospital or residential care, rather than to a palliative care service. With regard to accessing hospice care, De Vries & Nowell (2011) reviewed 288 case notes of admissions to a local UK hospice over three months and concluded that the admission of older people with dementia had slightly increased but remains small.

Disability presents as another area in which access and decision-making may be constrained by carer and provider perceptions. An ethnographic study by Tuffrey-Wijne (2009) involved observations of care of thirteen patients with learning disability who had cancer. Attribution of symptoms to attention seeking behaviour delayed the diagnosis in ten patients. Those individuals with learning disability had limited involvement in treatment decisions primarily due to professional and carer assumptions around ability to cope with treatment including capacity and understanding. Some participants displayed high anxiety in not knowing what was wrong and remained dependent and vulnerable. It is noteworthy that phase two did not identify further evidence concerning disability and access to hospice care, suggesting that future policy should revisit palliative care support for those with learning disability.

There are inequities around access to hospice care with regard to ethnicity (Quality Care Commission, 2016). Coupland et al. (2011) explored the Cancer Registry figures for cancer deaths in South East England between 1998 and 2006. This work identified that BAME groups are more likely to die in hospital without palliative care support; in contrast, white groups are more likely to attend hospice services. Similar findings are reflected in the work of Koffman et al. (2014) which explored the Office for National Statistics (ONS) mortality data from 2001-2014 in the London area. This study identified that those from Asia, Africa and the Caribbean are more likely to die in hospital. Sharpe et al. (2015) explored mortality data, census data and hospital episode for 2001-2009 in Scotland and identified that all ethnic groups, apart from white affluent Scottish patients were more likely to die in hospital, rather than at home or hospice. It was not possible to explain these figures but issues of deprivation as well as cultural factors may play a significant role.

Gender appears to impact on access to services. For example, Laird & Fallon (2009) present a literature review of palliative care services for older patients with breast cancer. Whilst breast cancer is common in later life, palliative care is lacking in supporting older women. Reasons for this include misdiagnosis due to co-morbidities resulting in referral to long-term rather than palliative care services. Williams et al. (2017) conducted focus groups with older people discussing vignettes around advance care planning, and similarly identified that women are often more likely to adopt a caring role, but are often left requiring care as they in turn age. Such findings suggest that palliative care access can be difficult for older women, so reducing their ability to exercise choice.

### **3.5.5 Timeliness of information giving**

A literature review by Eyre (2010) asserts that district nurses have a key role in providing information to carers and patients in order to facilitate advance care planning and coordinate care. However, a number of studies have found that predicting end of life can be difficult, posing challenges around when to discuss end of life care, particularly with regard to patient readiness and hope. Almack et al. (2012) for example, explored qualitative data from the perspectives of

patients, health professionals and relatives involved in delivering palliative care services, and found that health professional concerns around hope and timing affected opportunities for advance care planning. In order to minimise untimely communications, Murtagh & Thorns (2006) utilised participant feedback from three UK hospices in order to assess a clinical tool designed to gauge readiness for receiving information. Findings indicated that patient satisfaction (satisfaction is acknowledged as a subjective measure) was positive regarding timing of discussions, and doctors indicated increased confidence in information giving. In comparison, Schiff et al. (2009) evaluated a tool designed to prompt discussion between carers and patients and hospital medical staff and found that paradoxically 84% of participants expressed that discussions around health preferences were important, but 50% did not want to discuss end-of-life preferences. This presents a challenge to information giving, particularly when communicating with patients and families using denial as a coping mechanism.

Broom et al. (2012, 2015) explore similar issues in the Australian context in which two qualitative studies explored medical practitioner and nurse experiences of supporting referral to hospice care. These studies identified that staff experienced discussions around transition as emotional labour, requiring skilled evaluation in knowing how much or how little information to provide. Similarly, Gardiner et al (2011b) conducted a literature review around transition from curative to palliative care, and captured that how transition is conceptualised by health professionals (either as a clear shift or as an emotional and fragile experience) has implications for patient/professional conversations. MacArtney et al. (2015a) in the Australian context explored the patient experience of transition to hospice care, and captured patient resistance toward suggestions of hospice care. MacArtney et al. (2015a) suggest that acceptance of hospice care could be aided by a deeper awareness of what hospice care is and what it offers, however, initiating such conversations requires emotional resilience on the part of both patient and health professional.

There is evidence that the availability of services influences information giving. Seymour et al. (2010) for example, conducted a qualitative study with twenty community nurses in order to explore experiences of advance care planning

and care decisions. Nursing staff regarded advance care planning as a positive intervention, but barriers included issues of education, timeliness, and the availability of resources to support wishes. Minto & Strickland (2011) capture a similar finding in a small qualitative study in which three general practitioners and three district nurses explored their experiences of advance care planning with patients. Participants identified that the emotional labour evoked in initiating discussions was harder when resources to support care wishes were not available, adding a further dynamic to the complexity of 'managing' difficult conversations.

### **3.5.6 Dissonance in service providers and patient and carer understandings of services**

A number of studies capture that professional and lay understandings of needs and expectations can vary. A small qualitative study, (Tomlinson et al. 2011) evaluated the impact of written information for patients in a UK hospice, and argued that health professionals use terminology that is confusing for lay people, and therefore most people do not understand the purpose of hospice care prior to admission. In a larger study, Mcilpatrick et al. (2014) explored lay understandings of palliative care in using telephone interviews with fifty members of the public. This study identified that awareness and perceptions of hospice and palliative care generally are unclear, unless informed by prior experience.

There is a possibility that lack of awareness around palliative care could lead to dissonance in the purpose of services between service providers and service users. The controversy surrounding the Liverpool Care pathway and resultant report "More Care, Less Pathway" (Neuberger 2013) highlights how understandings and expectations can differ between service users and professionals. Regarding hospice care, Needham & Newbury (2004) evaluated patient centred goal setting in a hospice setting using proxy and retrospective data collected during a 6-month period. A record of goal attainment was recorded at discharge or death. The findings suggest that staff focused on

physical care, in contrast to patients and carers who focused on regaining or maintaining functional ability. Bradley et al. (2011) capture a further aspect of dissonance in a literature review exploring patient perspectives of attending day hospice services and suggest that psychosocial benefits and reduced isolation were highly valued by patients but that these aspects were harder to quantify as a quality measure. De Vries et al. (2012) in a study involving five patient cases (including interviews with patient, carer and health professionals) attending a hospice day unit identified similar findings. Although only a small study, the findings resonate with Bradley, et al. (2011) in that patients valued the psychosocial support, with concerns around discharge, whilst staff felt that a rolling programme of admission prevented dependency and widened access to others.

Work by Oliviere & Munroe (2004) identified issues of inequality and access to palliative care for BAME groups and similar findings are reported in the more recent "A Different Ending" (Quality Care Commission 2016). A number of studies explore possible reasons for lack of hospice use by BAME groups. Redman et al. (2008) for example, provide a literature review of UK Black, Asian and Minority Ethnic groups (BAME) in relation to cancer and palliative care, which suggests that cultural understandings may exacerbate difference in hospice use. Redman et al. (2008) explored issues around access to a range of services including cancer screening, and palliative care referral. This work asserts that palliative care provision may exclude BAME groups due to professional assumptions around need, leading to culturally insensitive care. Similarly, Koffman & Higginson (2001) examined the experiences of carers of deceased Black Caribbean first generation elders in South London and found that Black Caribbean patients had less access to information and palliative services than did white patients. Worth et al. (2009) in a qualitative study of Sikh and Muslim patients in Scotland also identified cultural difference between service user and professional expectations of services, particularly as Sikh and Muslim communities held a strong fatalistic belief in faith that was at odds with professional services, often resulting in mistrust and dissatisfaction of services. Later work by Cowan (2014) explored the experience of caring within the Sikh community in South East England and identified that services were perceived

as unsupportive, and family care was preferred, (although it is suggested that some responses were partly influenced by a lack of awareness of palliative support available). Venkatasalu et al. (2013) also explored cultural differences in perspectives on conversations about death and dying, using a series of focus groups and semi-structured interviews with fifty-five older people of south Asian origin in London. This work suggests a cultural avoidance of discussions around death, and generational dynamics in which younger family members aim to protect older relatives from such discussions (although there is acknowledgement this may not hold true for future generations), thus presenting a challenge to Western professional discourses on advance care planning.

### **3.6 Discussion**

This review identifies that a number of factors shape choice, and decisions with regard to use of hospice services, and captures inequities in access to services, particularly around non-cancer conditions such as dementia. Some of these lie at the individual level and include issues around knowledge of services, perceptions of place and carer support. Wider structural factors exist around funding; and availability of services and issues of social inequalities around age, gender, ethnicity and social deprivation.

More recent policy emphasis on home care has led to a more pointed focus on the needs of carers, and a growing recognition of the need to meet the physical, psychological and bereavement demands faced by carers. Carers as well as patients require supportive information giving and there is evidence of a growing discourse around public health and awareness in relation to palliative care and choice (Kellehear et al. 2007; Sallnow et al. 2016). However, timeliness of information around when and how to engage in difficult dialogue appears to cause professional anxiety. The literature suggests that for health professionals, difficult conversations are a complex balancing of maintaining hope, assessing readiness, providing accessible information, whilst also acknowledging denial as a legitimate coping mechanism. However to avoid

conversations reduces opportunities for information, choice and access to end of life care provision.

There has been an emphasis on place of death at home in providing a marker of good quality end of life care. However, the National Institute for Health Research (2015) and Pollock (2015) challenge the assumption that place of death is a priority for all patients. Providing service information and offering choice suggests that patient preference will be available, and yet in the context of austerity economics, this may not be the case. A commissioning emphasis on efficiency and cost effectiveness is driving demand for admissions tools to determine 'appropriateness' of admission. Understandings of 'appropriateness' however, may be contested and present a further possible area of dissonance between service users and health professionals, particularly with regard to non-cancer conditions.

### **3.7 Conclusion**

This literature review aimed to explore the factors that enable or constrain choice in accessing hospice services. Further insights into how choice and decisions shape access to palliative care services would be of value particularly as advance care planning is an increasing feature of UK care provision. An evaluation of how key stakeholders including carers, patients, professionals and service providers facilitate and negotiate the complexities involved in end of life care planning may help to elucidate how people access hospice services and how people negotiate 'choice' in end-of-life care. The literature review has therefore helped to inform the study design and the following aims:

- To explore how service users (patient and carers) facing end-of-life come to use hospice services;
- To examine how individuals make sense of choice within the context of palliative care;
- To explore the impact of ethnicity, age and gender on choice around hospice care;

- To explore how patient, carers and health care staff negotiate care decisions;
- Finally, to consider the role of end-of-life care planning tools in facilitating future care decisions.

The following chapter will explore the methodology underpinning the study design, which intends to address these aims.

Table 3: Phase One: Summary of selected papers 1998—2010.

Author/Date/Title	Research Question	Study Design	Sample	Findings
<p>Addington-Hall J.M. &amp; O' Callaghan (2009) A comparison of the quality of care provided to cancer patients in the UK in the last three months of life in in-patient hospices compared with hospitals, from the perspective of bereaved relatives: results from a survey using the VOICES questionnaire. <i>Palliative Medicine</i> 23(3) 190-197.</p>	<p>How do carers compare hospital versus hospice care at end-of-life?</p>	<p>Retrospective survey using VOICES questionnaire completed by carers.</p>	<p>40 informal carers screened to ensure that the deceased had experienced both hospice and hospital in patient care in the three months prior to death.</p>	<p>13 variables explored of which 8 variables indicated significant differences in care. Hospice care rated as more effective in terms of pain management, communication, medical and personal care and attendance to dignity and as well as greater involvement in decision-making within the hospice setting.</p>
<p>Agnew et al. (2010) Bereavement needs assessment in specialist palliative care: a review of the literature. <i>Palliative Medicine</i> 24(1) 46-59.</p>	<p>Which bereavement tools would be appropriate for identifying bereavement support needs in UK palliative care context?</p>	<p>Literature review focussing on bereavement tools in international context.</p>	<p>59 papers identified allowing comparison of bereavement assessment tools.</p>	<p>Papers divided into two categories: normal or complicated bereavement. Identifies 10 models of bereavement risk assessment. Identifies importance of bereavement assessment tools and highlights that the Adult Attitude to Grief Scale offers potential in UK context but requires further validation.</p>
<p>Bradley, Frizelle &amp; Johnson (2011). Patients' psychosocial experiences of attending Specialist Palliative Day Care: A systematic review. <i>Palliative</i></p>	<p>To explore patient reflections on attending a palliative day care centre.</p>	<p>Systematic literature review.</p>	<p>Twelve studies included.</p>	<p>Specialist palliative day units offer opportunities for social interaction and support, communication, and social activities. These interventions appear to support hope, identity and ability to cope with changes to self and identity.</p>

<i>medicine</i> 25(3) 210-228.				
<b>Cotterell (2008)</b> Striving for independence: experiences and needs of service users with life limiting conditions. <i>Journal of advanced nursing</i> 62(6) 665-673.	What are experiences of care for service users with life limiting conditions?	Participatory qualitative study exploring impact of health and social care services on service user's experiences of living with life-limiting conditions.	25 participants recruited from service user and support groups 64% were women; 56% had a cancer diagnosis, with the age range was 38–85 years.	8 themes identified Independence/dependence, diagnosis, fear, anger/frustration, grief, relationships, difference/individuality and services. Overarching theme identifies balance between retaining/maintaining independence and requiring further support.
<b>Enes et al. (2004)</b> Discharging patients from hospice to nursing home: a retrospective case note review. <i>International journal of palliative nursing</i> 10(3) 124-130.	How does the process of transfer from hospice to long term care impact on service users?	Retrospective case note review from one UK hospice including follow up of patients transferred to long-term care.	Case notes identified 16 patients requiring transfer to long-term care during 1999-2000.	16 patients discharged to nursing home with a mean length of stay in a nursing home of 8 weeks. Response to transfer vary from distress to preference for long-term care. Relocation stress may affect mortality.
<b>Eyre (2010)</b> Supporting informal carers of dying patients: the district nurse's role. <i>Nursing Standard</i> 24(22) 43-48.	What is the role of the district nurse in supporting end-of-life care?	Literature review identifying key skills and role of district nurse in end-of-life care.	Number of papers unspecified.	District nurses should have the skills to support end-of-life care including: information giving; supporting patient comfort; safety and security; emotional psychological and spiritual support and care in the last hours, particularly as often providing out-of-hours service and often key coordinators of services. Recommends Liverpool End-of-life and Gold Standards framework as important support interventions.

<p>Fergus et al. (2008) Is a STAS-based tool valid to triage patients at a specialist palliative care inpatient unit? <i>International journal of palliative nursing</i> 14(1) 24-29.</p>	<p>How effective is the Support Team Assessment Schedule in prioritising admissions to hospice?</p>	<p>Triangulation of rating scores between doctors, nurses and bed managers using an assessment tool.</p>	<p>127 patients admitted to an in-patient hospice assessed by clinicians for appropriateness of admission.</p>	<p>Results indicate poor inter-rater reliability of tool. Admission information incomplete or using secondary data resulting in decisions shaped by varying clinical and subjective judgement. Tool not validated.</p>
<p>Gott et al. (2004) Older people's views about home as a place of care at the end of life. <i>Palliative Medicine</i> 18(5) 460-467.</p>	<p>How do older people regard palliative care in the home setting?</p>	<p>Qualitative study using vignettes to stimulate discussion around older people's end-of-life place of care preferences.</p>	<p>Eight focus groups held with 52 older people. 45 semi structured interviews conducted with older people selected from GP records from a range of socioeconomic localities and three age bands; 65-74; 75-84; and &gt;85 years.</p>	<p>Home emerged as a social construct rather than a spatial location and symbolised familiarity, autonomy and identity. Concerns around dying at home focused on not having a carer, not wanting to be a burden, and professional home care seen as intrusive. .</p>
<p>Gott et al. (2008) At odds with the End of Life Care Strategy. <i>Nursing Older People</i> 20(7) 24-27.</p>	<p>How does the end-of-life care strategy support older people?</p>	<p>Commentary on end-of-life care strategy in relation to older people</p>	<p>Commentary</p>	<p>Challenges assumptions around home as preferred place of care when dying. Older people concerned around carer burden, particularly for younger carers.</p>
<p>Grande et al. (2009) Supporting lay carers in end of life care: current gaps and future priorities. <i>Palliative Medicine</i> 23(4) 339-344.</p>	<p>What are the needs of carers providing care at end-of-life?</p>	<p>Review of evidence around support needs highlighted for discussion at end of life conference.</p>	<p>International leads explore current evidence around interventions to support informal carers</p>	<p>Identifies lack of longitudinal studies as well as lack of validated tool to monitor carers on going needs at end-of-life. Care giving entails considerable cost for primary carers and wider family, including emotional, social, financial and physical cost and increased mortality. Support currently focuses on post death</p>

				interventions rather than earlier intervention.
Kennedy et al. (2009) Key stakeholders' experiences and views of the NHS End of Life Care Programme: findings from a national evaluation. <i>Palliative medicine</i> 23(4) 283-294.	What are the views of key leads in implementing the NHS end-of-life care programme?	Qualitative interviews exploring stakeholders perceptions of the impact of the NHS end-of-life care programme (2006-2007)	Purposive sample of 37 leads involved in implementation of NHS programme (selected from primary care trusts, directors/ managers of workforce development).	Overall stakeholders were positive regarding implementation of end-of-life care strategies in to mainstream sector. Concerns regarding sustainability of the programme as initiatives supported by highly motivated individuals. .
Kessler et al. (2005) Social class and access to specialist palliative care services. <i>Palliative medicine</i> 19(2) 105-110.	How does social class impact on care at end-of-life?	Mixed methods involving retrospective data from Public Health Mortality databases, and use of standard occupational classification, along with qualitative interviews.	Cross sectional survey of n=960 cancer deaths in South Bristol, between Sept 1999 and Dec 2002. 18 carers of deceased identified from GP records.	No difference in social class between those dying at hospital or home but individuals from class V less likely to die in hospice and more passive in requiring information. Carers from social class IV and V e more likely to have support from families than class I/II. High carer anxiety noted in lone carers. Unrealistic expectations of bed availability noted.
Koffman & Higginson (2001) Accounts of carers satisfaction with health care at the end of life: A comparison of first generation black Caribbean and white patients with advanced disease. <i>Palliative Medicine</i> 15(4) 337-345.	Are there differences in satisfaction between carers of Black Caribbean and white patients with progressive disease?	Quantitative survey design comparing levels of satisfaction.	50 interviews with white and black Caribbean relatives of 106 black Caribbean and 110 white deceased in 3 areas of South London in 1997-1998	Black Caribbean patients more likely to access acute hospital services. Satisfaction with community care poor and access difficult to negotiate. Health professionals require further training and support to ensure that services provide cultural sensitivity and equity.

<p>Laird &amp; Fallon. (2008) Palliative care in the elderly breast cancer patient. <i>Clinical oncology</i> 21(2) 131-139.</p>	<p>What is known around the care of elderly patients with breast cancer?</p>	<p>Review of pain management in elderly patients with breast cancer</p>	<p>Literature review relating to older women &gt;70 years.</p>	<p>Breast cancer most common in 8th decade but palliative care is lacking in supporting older women. Co morbidities often exist which preclude patients from palliative care. Palliative needs should include review of carer support available.</p>
<p>Lawton (1998) Contemporary hospice care: the sequestration of the unbounded body and 'dirty dying'. <i>Sociology of health &amp; illness</i> 20(2) 121.</p>	<p>Who is admitted to in-patient hospice care and why?</p>	<p>Explores criteria for patient admission to in-patient hospice care.</p>	<p>Ethnographic study of hospice care over a period of 10 months.</p>	<p>Theoretical framework of bounded and unbounded body. Hospice admission associated with 'unbounded body'. Loss of self and identity prevalent in concept of unbounded body (social death).</p>
<p>McIlfatrick, (2007) Assessing palliative care needs: views of patients, informal carers and healthcare professionals. <i>Journal of advanced nursing</i> 57(1) 77-86.</p>	<p>What are the palliative care needs identified by patients, carers and professionals at end-of-life?</p>	<p>Qualitative study involving focus groups with service providers and semi-structured interviews with lay carers.</p>	<p>Purposive sample of 24 lay carers and patients with non-cancer as well as malignant disease and 52 interprofessional palliative care providers.</p>	<p>Themes include difficulties in defining palliative care, communication, coordination and continuity of care, issues around accessing to community care. Patients and carers often 'battle' against the system. Professionals identify funding as an issue in care provision.</p>
<p>McQuillan et al (2007) Indigenous ethnic minorities and palliative care: exploring the views of Irish Travellers and palliative care staff. <i>Palliative medicine</i> 21(7) 635-641.</p>	<p>What is the experience of palliative care for travellers?</p>	<p>Mixed method qualitative study</p>	<p>2 focus groups and 14 one-to-one interviews, including travellers and health professionals. Postal Survey questionnaire to 215 palliative care staff.</p>	<p>Perceptions and understandings differ between professional and travellers groups. Key themes: Family important in end-of-life care but travellers are sensitive that hospital/hospice settings regard large families negatively. Hope is very important but can impact communication with resulting delays in accessing diagnosis, treatment and admission. Care at home acceptable but not death. Staff disadvantaged in terms of training and understandings.</p>

<p>Murtagh &amp; Thorns. (2006) Evaluation and ethical review of a tool to explore patient preferences for information and involvement in decision-making. <i>Journal of medical ethics</i> 32(6) 311-315.</p>	<p>Can a clinical tool assess patient preference for information and involvement in decision-making?</p>	<p>Quantitative questionnaire delivered before and after administered tool.</p>	<p>3 UK hospices participated and 61 completed questionnaire administered 3-14 days post admission. Medics completed questionnaire regarding confidence in information giving.</p>	<p>Trial of tool elicited discussion of preferences that were valued as much as the tool. Patient satisfaction with information giving significantly improved following intervention of questionnaire. Tool enabled confidence in medical staff.</p>
<p>Needham &amp; Newbury (2004) Goal setting as a measure of outcome in palliative care. <i>Palliative medicine</i> 18(5) 444-451.</p>	<p>What is the impact of joint goal setting in a palliative care unit on patients and staff?</p>	<p>Clinical audit of goal setting in admissions to an 8 bedded UK hospice in 6-month period.</p>	<p>97 patients, 74 carers and 120 hospice staff completed a record of goals within 24 hours of admission. Achievement of goals assessed at close of hospice stay.</p>	<p>Only 15 patients and 9 carers thought that only some or none of their goals were achieved. The audit enhanced multidisciplinary discussions. Goals changed over time. Carers and patients focus on wanting to regain function whilst staff focus on problem solving particularly pain management.</p>
<p>Redman et al. (2008) Critical review of literature on ethnicity and health in relation to cancer and palliative care in the United Kingdom. . <i>Diversity in Health and Social Care</i> 5(2) 137-150.</p>	<p>What is known about cancer care and palliative care for Black and Ethnic Minority groups (BAME)?</p>	<p>Systematic literature review</p>	<p>Search terms captured concepts of 'race' and 'ethnicity' and health care and identified 31 articles published 2000-2005.</p>	<p>Risks conceptualised in terms of health risks, treatment accessibility of services and outcomes. Prevalence of cancer increasing in BAME groups. BAME groups less likely access palliative care services. Professional palliative care services assume patients would prefer home care. However if crisis of condition or care occurred BAME groups are more likely to die in hospital. Cultural insensitivity compounds differences in treatment and support.</p>
<p>Rigby, Payne &amp; Froggatt (2010) Review: what evidence is there about the specific environmental needs of older people who are near the end of life and are cared for in hospices or similar</p>	<p>How does environment impact on older people receiving end-of-life care?</p>	<p>Explore physical environment preferences in end-of-life care of older people &gt;65.</p>	<p>Narrative literature review of 29 papers.</p>	<p>Key themes include homeliness: use of personal effects regarded as important; social interaction was important but some patients enjoyed sharing space, although at times noise, staff and other patients could be intrusive. The environment is often ill designed to monitor dying patient, or support families</p>

institutions? A literature review. <i>Palliative Medicine</i> 24(3) 268-285.				who wish to be present overnight. Spirituality valued along with a place to provide meditation or worship.
Schiff et al. (2008) Advance end-of-life healthcare planning in an acute NHS hospital setting; development and evaluation of the Expression of Healthcare Preferences (EHP) document. <i>Age &amp; Ageing</i> 38(1) 81-85.	How acceptable and effective is a healthcare preference tool in identifying end of-life care needs?	Evaluation of a tool designed to aid older patients in hospital setting record end-of-life healthcare preferences.	Quantitative questionnaire survey administered to patients over 60 years regarding end-of-life preferences. 56 patients responded.	84% felt that expression of health preferences was important. 50% did not want to discuss end-of-life preferences and did not feel it relevant to them at that time. The survey enabled information giving and prompted discussions between patients and those close to them as well as medical staff.
Seymour et al. (2007) Hospice or home? Expectations of end care among white and Chinese older people in the UK. <i>Sociology of health &amp; illness</i> 29(6) 872-890.	How do Chinese and white older people compare in perceptions around end -of-life care?	Participatory qualitative research using focus groups and one-to-one interviews	White older people (77) and Chinese older people (92) explored vignettes around of end-of-life preferences.	Identifies cultural differences in preferences for place of death. White elders associate hospices with dying. Home preferred as place of care albeit with concerns of being a burden to younger generation. Hospice care regarded as less impersonal than dying in hospital. Chinese elders are less familiar with hospice or palliative care. Hospice care was a place of death and reflected poorly on the family. Hospital care perceived to provide greater hope and allow families to be present. Dying at home is potentially contaminating to home property.
Thomas, Morris & Clark. (2004) Place of death: preferences among cancer patients and their carers. <i>Social science &amp; medicine</i> 58(12) 2431-2444.	What shapes choice around place of care preference for cancer patients and carers?	Qualitative interviews.	One-to-one interviews with 41 terminally ill cancer patients and 18 informal carers referred from specialist palliative care teams from referral and	Preferences of place of care are pragmatic and shaped by availability of carers, experiences of care providers, living arrangements and beliefs about death and dying. Not all decisions based on positive choices therefore, recommends support for home death but advocates continued support of in-patient

			repeated at 2-4 week intervals until death. Co resident carers interviewed at patient referral and post death.	hospice patients whose choices are constrained by a variety of factors.
Tuffrey, Wijne et al. (2009) The preferred place of care for people who are dying. <i>Learning Disability Practice</i> 12(6) 16-21.	What the care experiences of people with learning disability who have cancer?	To provide insight in to experiences and needs of people with learning disability who have cancer.	13 people with learning disability. Mean age 53 years. All had diagnosis of cancer. 8 died during the study period and lived in either residential home, own flats, parental home and foster carer home	Individuals with learning disability had biography of dependent lives, with history of abuse and vulnerability. Diagnosis of cancer is often late as symptoms attributed to attention seeking. Little involvement in treatment decisions and information giving restricted by carer perceptions and lack of confidence in health and social care professionals in talking to people with learning disability.
Worth et al. (2009) Vulnerability and access to care for South Asian Sikh and Muslim patients with life limiting illness in Scotland: prospective longitudinal qualitative study. <i>BMJ</i> 338(feb03_1) b183.	What are the experiences of South Asian Sikh and Muslim patients with life limiting conditions?	Prospective longitudinal qualitative design.	Participants included 25 purposively selected South Asian, Sikh and Muslim patients, 18 family carers. Patients interviewed 3 times over 18 months either at home or by telephone. 20 key health professionals. In total 90 interviews recorded.	Barriers to care include lack of resources, institutional and personal racial and religious discrimination, and limited awareness and understanding among South Asian people of hospice care. Argues for recognition of 'risk' factors in identifying vulnerability.

Table 4: Phase Two: Summary of selected papers 2010-2016				
Author/Date/Title	Research Question	Study Design	Sample	Findings
Broom et al. (2012) Specialists' experiences and perspectives on the timing of referral to palliative care: a qualitative study. <i>Journal Of Palliative Medicine</i> 15(11) 1248-1253	To examine how specialist practitioners decide when referral to palliative services is appropriate.	Qualitative study using framework analysis.	Twenty medical practitioners working in various specialisms in Australia	Themes identify that timing of referral shaped by symptoms and perception of patient need, as well as family caregiver and patient readiness to discuss palliative care. Referral is also dependent on interprofessional relationships within services. Delaying referral could reduce quality of life.
Broom & Kirby (2013) The end of life and the family: hospice patients' views on dying as relational. <i>Sociology of Health &amp; Illness</i> 35(4) 499-513.	To explore the perceptions and experiences of patients in the last few weeks of life with regard to family relations	Qualitative study.	20 inpatients identified by clinical staff as 'stable' in an Australian hospice.	End of life is relational within a set of family dynamics and influenced by concepts of individualisation, and contemporary shifts in family dynamics around availability and expectation.
Broom et al. (2015) Negotiating futility, managing emotions: nursing the transition to palliative care. <i>Qualitative Health Research</i> 25(3) 299-309.	To examine how nurses manage patient transition to palliative care.	Qualitative study using grounded theory.	20 nurses from across two Australian hospitals involved in supporting patient transition to palliative care.	Identifies that communication around transition to palliative care triggers intrapersonal and interprofessional tensions and staff express emotional burden in supporting transition.
Campbell et al. (2010) Exploring differences in referrals to a hospice at home service in two socio-economically distinct areas of Manchester, UK. <i>Palliative</i>	What are the differences in referral to a hospice at home service in the two socio-economically	Exploration of secondary data using UK National statistics 2001, North West Intelligence Service 2004 and Hospice at home referral	Two areas of Manchester, UK with differing levels of deprivation.	Referral rates to hospice at home lower in areas of poorer deprivation, despite high incidence of cancer. The factors of this are unclear and may reflect in equality in access or differences in preference of service.

<i>Medicine</i> 24(4) 403-409.	distinct areas of Manchester, UK	data 2004-2006.		
Carduff et al. (2016) Piloting a new approach in primary care to identify, assess and support carers of people with terminal illnesses: a feasibility study. <i>BMC Family Practice</i> 17.	To pilot the use of the Carers Support And Needs Assessment Tool (CSNAT) to identify, assess and support carers of people with terminal illnesses	Qualitative study evaluating interviews with carers who had received a carer support intervention and completed the CSNAT..	25 carers of people with terminal illness identified via four General Practice registers and who had participated in a carer support intervention	21 out of 25 carers identified as having support needs. Carers valued the assessment tool and identification of support needs. Recommends use of existing records to identify carers and whole system approach to raising awareness of carer needs.
Cowan (2014) The lived experiences of the Sikh population of southeast England when caring for a dying relative at home. <i>International Journal of Palliative Nursing</i> 20(4) 179-186.	To explore and understand the experiences of the Sikh population of south east England when caring for a dying relative at home without support from a specialist palliative care service	Qualitative interviews using interpretive phenomenology	Six semi-structured interviews conducted with six bereaved Sikh carers	Cultural expectations around faith and role shape carer expectations of adopting the care role. This role could be challenging. Carers also regarded professional services with mistrust and there was a lack of awareness around support services.
Coupland (2011) Does place of death from cancer vary between ethnic groups in South East England? <i>Palliative Medicine</i> 25(4) 314-322.	To explore whether place of death varies between different ethnic groups	Data from the Thames registry for South East England and data from ONS explored the relationship between place of death,	Data of 101,516 deaths from cancer in South East England from 1998-2006 analysed using linear regression around	People from more deprived areas are more likely to die in a hospital. Asian, black, Afro Caribbean and Chinese patients are more likely than white people to die in hospital. Pakistani, Indian and Bangladeshi patients with cancer significantly less

		measure of deprivation and ethnicity.	variables of place of death, and self-reported ethnicity.	likely than white patients to die in a hospice.  Data does not reveal whether differences are due to barriers or preference.
De Vries & Nowell (2011) Dementia deaths in hospice: a retrospective case note audit. <i>International Journal of Palliative Nursing</i> 17(12) 581-585.	To identify the number of patients admitted to a UK hospice, over a three-month period, with either dementia as primary diagnosis or co morbidity	Retrospective case note audit	208 case notes of patients admitted to a UK hospice over 65 years explored for diagnosis on admission.	The number of patients admitted having a diagnosis of dementia has marginally increased: only 2% identified as having a primary diagnosis of dementia and 9% as having dementia as a co morbidity.
De Vries, Wells, & Plaskota (2012) Evaluation of an admission and discharge programme at a UK specialist palliative day hospice. <i>International journal of palliative nursing</i> 18(6) 275-281.	To explore the experiences of patients, carers and service providers who used a hospice day unit as part of a rolling programme of care.	Case study approach based on one patient per case and qualitative interviews.	Five case studies involving qualitative interviews with patients, carers, and key health professionals involved in supporting care.	Reasons for discharge and admission are unclear. Admission criteria focused on symptom control generally. Patients value the therapeutic environment. Staff perceive that a rolling programme of admission and discharge avoided dependency, however, discharge results in deterioration in patient health and wellbeing.
Dixon et al. (2015) <i>Equity in the provision of palliative care in the UK: review of evidence</i> . Discussion Papers, 2894. London School of Economics and Political Science, Personal Social Services Research Unit, London, UK.	To explore evidence on equity in palliative care and implications of extending palliative care.	Rapid review of current evidence using academic datasets and grey literature.	Literature and data sets from National survey of bereaved people in England 2013, Minimum dataset for specialist palliative care services and the Office for National Statistics.	Inequities identified in relation to diagnosis, deprivation and age. Evidence suggests that people over 80 years are less likely to access palliative services. Evidence with regard to ethnicity and access is mixed.

			Variables examined include age, diagnosis, area deprivation, ethnic background.	
Ewing & Grande (2013) Development of a Carer Support Needs Assessment Tool (CSNAT) for end-of-life care practice at home: A qualitative study. <i>Palliative Medicine</i> 27(3) 244-256.	To develop a tool for identifying carer support needs	Qualitative focus group and telephone interviews. Thematic analysis.	75 bereaved carers of family or friends from five UK hospice at home services.	Development of the Carers Support Needs Assessment Tool (CSNAT). The tool provides an evidence based approach to identifying carer needs suitable for routine practice.
Gage et al. (2015) Impact of a hospice rapid response service on preferred place of death, and costs. <i>BMC Palliative Care</i> (2015) 14: 75.	To evaluate a rapid response service using the measures of cost and preferred place of death.	Random stepped design- using data from hospice services within three areas over 18 months. Demographic data, preferences for place of death and service use data explored using logistic regression analysis.	953 patients admitted to hospice provider in 3 areas and referred to rapid response team.	Financial calculation of services suggest rapid response services are cost neutral. Non-users of the service tended to have higher hospital costs. The probability of dying in the preferred place of death was enhanced by referral to the rapid response team, although having a carer appeared to impact on likelihood of dying in the preferred place of care (particularly home).
Gardiner et al. (2011a) Barriers to providing palliative care for older people in acute hospitals. <i>Age and Ageing</i> . 40(2), pp.233-238.	To explore professional perceptions of barriers to older people in accessing palliative care within the acute hospital setting	Qualitative focus groups using thematic analysis	Four focus groups with professionals working in General Practice, two acute hospitals and two hospice settings (n=58).	Barriers to optimal palliative care include lack of resources, perceptions of need, and a focus on curative interventions.

<p>Gardiner et al. (2011b) Exploring the transition from curative care to palliative care: a systematic review of the literature. <i>British Medical Journal of Supportive &amp; Palliative Care</i> 20(1) 56-63.</p>	<p>To explore patient and professional experiences of transition from curative to palliative care.</p>	<p>Literature review</p>	<p>Systematic search using 4 databases. 12 papers identified and synthesized using thematic description.</p>	<p>Transition is complex. Patient and carer experiences of transition are complex, recognition and conceptualisation of transition phase is challenging. A phased approach to transition recommended.</p>
<p>Gardiner et al. (2014) Exploring the financial impact of caring for family members receiving palliative and end-of-life care: A systematic review of the literature. <i>Palliative medicine</i> 28(5) 375-390.</p>	<p>To explore financial impact of family caring at end of life</p>	<p>Literature review using Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) guidelines.</p>	<p>Systematic review of 7 databases. 21 articles identified.</p>	<p>The financial impact on caregivers is often unrecognised but economic models of care should acknowledge the financial impact on family carers given the shift toward community palliative care.</p>
<p>Harrop et al. (2014) "It's alright to ask for help": findings from a qualitative study exploring the information and support needs of family carers at the end of life. <i>BMC, Palliative Care</i> 13.</p>	<p>Explore the information and support needs of family carers and health professionals</p>	<p>Qualitative approach utilizing a critical realist approach.</p>	<p>Focus groups conducted with carers both current and bereaved, health care assistants and community specialist nurses (n=16) who were identified through a UK hospice.</p>	<p>Three themes identified carer knowledge and competence, carer preparation to care, and identity and confidence. Recommends resource packs and signposting to help carers recognise own needs and access support.</p>
<p>Hunt et al. (2014) End-of-Life Care and Preferences for Place of Death among the Oldest Old: Results of a Population-Based Survey Using VOICES-Short Form. <i>Journal of Palliative Medicine</i> 17(2) 176-182.</p>	<p>To explore experiences of end of life care and reported preference for place of death in the oldest old.</p>	<p>Survey design identifying bereaved carers using the Office for National Statistics extracted all deaths registered in two English health districts between</p>	<p>Bereaved carers identified using the Office for National Statistics to identify registered deaths in two English health districts between October 2009 and April 2010.</p>	<p>Relatives of the 'oldest old' report poor quality of care in the last two days of care and reduced choice in place of care. Those over 85 years were most likely to die in a hospital or care home and a very small minority died in a hospice (1%).</p>

		October 2009 and April 2010.	(n=473).	
Kirby et al. (2014a) Medical specialists' motivations for referral to specialist palliative care: a qualitative study. <i>BMJ Supportive &amp; Palliative Care</i> 4(3) 277-284	To explore the ways in which medical specialists manage and experience the referral of patients to palliative care services.	Qualitative interpretivist design focusing on the referral experience around a particular patient.	20 medical specialists who had referred a patient in 2010 to a large specialist palliative care centre in Australia interviewed during 2011-12. Sample included a mix of gender, seniority and specialty.	Conversations around referral to palliative services generally involve medics, family and patients. Family members are influential in shaping decisions. Medics identified families as either a resource or a 'complication' in facilitating referral.
Kirby et al.(2014b) Families and the transition to specialist palliative care. <i>Mortality</i> 19(4) 323-341.	To explore how medical specialists reflect on discussions around referral to palliative care with patients and families	Qualitative design.	20 medical specialists who had referred a patient in 2010 to a large specialist palliative care centre in Australia were interviewed during 2011-12 and included a mix of gender, seniority and specialty	'Conditional rationality' shaped conversations between health professional, patient and family around referral. Family dynamics and biography were important factors in referral to palliative care.
Koffman et al (2014) Does Ethnicity Affect Where People with Cancer Die? A Population-Based 10-Year Study. <i>Plos One</i> 9(4).	To examine place of death of BAME patients with cancer in the UK.	Quantitative study using ONS population data around place of death and ethnic group.	Mortality data for 2001-2010 on patients aged over 65 years identified by place of birth as ethnicity and place of death	Generally, the number of home deaths is increasing and hospital deaths decreasing. Home death less likely for those born in the Caribbean. BAME groups more likely to die in hospital than home or hospice. Unknown if place of death determined by barriers or preference.

<p>Lowson et al. (2013) From 'conductor' to 'second fiddle': older adult care recipients' perspectives on transitions in family caring at hospital admission. <i>International Journal Of Nursing Studies</i> 50(9) 1197-1205.</p>	<p>To explore the experience of family caring for relatives requiring palliative support and transition to hospital settings</p>	<p>Qualitative Framework Analysis</p>	<p>27 patients with either heart failure or lung cancer aged over 75 years with experience of transition to hospital within the last 6 months and expected to have died with 12 months were contacted via oncology, heart failure and hospice nurses in North West England between 2009-2010</p>	<p>Carers act as 'conductors' in coordinating and managing care. Transition to hospital provided some assistance but the role of the caregiver was as a 'second fiddle' and carers work hard to ensure continuity of care. Acknowledgement of carers skills could assist in continuity of care across settings.</p>
<p>Milligan, C et al. (2016) Unpacking the impact of older adults' home death on family care-givers' experiences of home. <i>Health &amp; Place</i> 38 103-111.</p>	<p>To explore the impact on meaning and experience of home and caring for family carers supporting end of life and experiences of early post death period.</p>	<p>Qualitative framework analysis</p>	<p>59 carers recruited via GP from North West and South West locations in UK. Criteria included caring at end of life, for older person, with experience between 6 months to one year.</p>	<p>'Home' identified as a complex entity. Death at 'home' may not necessarily be death in a familiar place, as it can proceed movement into or out of a homes. Home death can alter the experience of home in terms of relationships, objects, actions, and socio spatial relations, and impact on bereavement. Deeper understandings of the disruption to home and relationships might enable more supportive interventions.</p>
<p>Mcilpatrick et al.(2014) Exploring public awareness and perceptions of palliative care: a qualitative study <i>Palliative Medicine</i> Mar. 28 (3) 273-80</p>	<p>To understand public understandings of palliative and hospice care.</p>	<p>Exploratory qualitative study.</p>	<p>50 telephone interviews with the public to explore perceptions of palliative care and services.</p>	<p>Understandings informed by prior experience. Palliative care interpreted as care in the last few days of life. Understandings of palliative care require further clarification and public awareness.</p>

<p>MacArtney et al. (2015) On resilience and acceptance in the transition to palliative care at the end of life. <i>Health: An Interdisciplinary Journal for the Social Study of Health, Illness &amp; Medicine</i> 19(3) 263-279.</p>	<p>To explore the lived experience of patients entering an in-patient specialist palliative care unit.</p>	<p>Qualitative approach to exploring lived experience.</p>	<p>Purposive sample of 40 patients based in a specialist palliative care unit within a hospital in Australia. Sample aged between 30 and 91 years.</p>	<p>Findings suggest that traditional models of transition from denial to acceptance do not capture the experience of patients who tended to express resilience in terms of resistance to hospice care. Hospice referral accepted at the point when curative treatment is constructed as having a negative impact on quality of life. There is some oscillation between resilience and acceptance.</p>
<p>Minto &amp; Strickland (2011)  Anticipating emotion: a qualitative study of advance care planning in the community setting. <i>International Journal of Palliative Nursing</i>. Vol. 17.5. 278-284</p>	<p>Study to explore factors influencing discussions around advance care planning in the community setting.</p>	<p>Qualitative study using an interpretative phenomenological approach</p>	<p>Primary care setting in Scotland identified GP practices and clinical nurse specialists in the community and General Practitioners. Six participants explored experiences of discussion advance care planning.</p>	<p>Participants identified that discussions could be distressing, for patients and practitioners. Managing expectations of carers and patients required sensitivity and skill. Availability of resources, particularly equipment effected advance care planning discussions.</p>
<p>Morris (2012) Advocating for palliative care for an ageing population: living to the end. <i>International Journal of Palliative Nursing</i>, 18, 420-421.</p>	<p>Discuss global response to an ageing population and palliative needs</p>	<p>Commentary</p>	<p>Identifies World Health Organisation and International Hospice Day as leading discussion around ageing and palliative care.</p>	<p>Commentary argues that the palliative care needs of older people are not adequately met and that demographic change presents future challenges for health care services. Consideration of palliative care for older people raises issues of quality of life early detection and quality of care.</p>
<p>Morris et al. (2015) Family carers providing support to a person dying in the home</p>	<p>To explore perspectives of family carers dying at home.</p>	<p>Narrative and systematic literature review</p>	<p>28 studies identified over period 2000-2013 from databases CINAHL,</p>	<p>Carers value home as a place of normality and bonding, although the home space was altered when dying at home. Support from formal care</p>

<p>setting: A narrative literature review. <i>Palliative Medicine</i> 29(6) 487-495.</p>			<p>Medline and PsycINFO.</p>	<p>organisations is valued for information giving and support for pain management. There are gaps in service provision carers may be isolated, with implications particularly for older carers.</p>
<p>Perrels et al. (2014) Place of death and end-of-life transitions experienced by very old people with differing cognitive status: Retrospective analysis of a prospective population-based cohort aged 85 and over. <i>Palliative Medicine</i> 28(3) 220-233</p>	<p>To explore end of life transitions for older people aged over 85 years with cognitive impairment</p>	<p>Analysis of mortality records and data from the longitudinal Cambridge City Over 75 Cohort around place of death and residence</p>	<p>283 records from those aged over 85 who had been interviewed one year before death were explored for place of residence, place of death and level of cognitive impairment</p>	<p>One third of community dwelling people over 85 years with severe cognitive impairment more likely to die in hospital and two thirds transferred to long-term care in months prior to death. None died in a hospice. Those residing in long-term care were more likely to remain until death. Recommendations focus on supporting good community as well as long-term care for older people with cognitive impairment.</p>
<p>Ryan et al. (2013) Symptom burden, palliative care need and predictors of physical and psychological discomfort in two UK hospitals. <i>BMC Palliative Care</i> 12 11-11.</p>	<p>To explore levels of physical and psychological burden in two hospital populations and level of palliative needs.</p>	<p>Quantitative survey of two hospitals over a two week period exploring patient demographics against two measures including the Gold Standards Framework Prognostic Indicator, and the Sheffield Profile for Assessment and Referral to Care (SPARC) tool..</p>	<p>Patient data from within a two-week period from two Northern Hospitals from n=514 patients. Of these n=185 indicated some degree of palliative care need.</p>	<p>Of those patients indicating palliative care needs, only 15 per cent referred to specialist palliative care services. The paper suggests that frail older patients with dementia have high burden but are less likely to have a referral to specialist palliative care services.</p>
<p>Robinson et al. (2015) A qualitative study exploring the benefits of hospital admissions from the perspectives of patients with palliative care needs. <i>Palliative Medicine</i> 29(8) 703-710.</p>	<p>To explore the perspectives of patients with palliative care needs who are admitted to hospital</p>	<p>Longitudinal Qualitative study using a critical realist approach around structure and experience.</p>	<p>Fourteen patients admitted to a New Zealand hospital between 2013-2014 and identified as having palliative need using the Gold Standards</p>	<p>Hospital admission can offer a sense of safety for patients and their family particularly if deterioration in condition. Hospital admission can prompt more help at home, provides a relief for family carers, and a sense of getting or feeling better. Findings suggest that policy constructs acute hospital care</p>

			Prognostic Indicator were interviewed within 48 hours of hospital admission and again one-week post discharge.	as a negative place of care for patients with palliative needs. However, patients and carers found benefits to hospital admission.
Sharpe, K, et al. (2013) Policy for home or hospice as the preferred place of death from cancer: Scottish health and ethnicity linkage study population cohort shows challenges across all ethnic groups in Scotland <i>BMJ Supportive &amp; Palliative Care</i> . 5 (4) 443-451	To explore relationships between ethnicity and place of death.	Use of census data to explore hospital episode and mortality data.	Comparison of hospital, home or hospital death between different ethnic groupings during 2001-2009 in the Scottish population.	Affluent white Scottish patients were more likely to die at home, or in a hospice and less likely to die in a hospital than other ethnic groups.
Sutton & Coast (2012) 'Choice is a small word with a huge meaning': autonomy and decision-making at the end of life. <i>Policy &amp; Politics</i> 40(2) 211.	To explore factors influencing older people's experience of choice and decision-making at end of life.	Qualitative study using grounded theory approach in one to one interviews with older people.	23 older people divided into 3 groups derived from general population, hospice and residential care. 15 women and 8 men identified aged 65-97.	Older people appear to find an unknown future illness difficult to anticipate in terms of care planning. Planning is often reactive and older people prefer to avoid being a burden to others. Recommends wider discussions with older people and their families in order to avoid undesired medical interventions at end of life.
Seamark et al. (2014) Dying at home: A qualitative study of family carers views of support provided by GPs community staff. <i>British Journal of General Practice</i> 64(629).	To explore carers perspectives of care which supported death at home.	Qualitative study using one to one interviews.	59 carers from Devon, Lancashire and Cumbria who had been bereaved in previous 6-24 months explored experiences of continuity of care	Large number of carers and changes in staff reduce continuity of care. Information and communication systems do not transfer information. Where continuity of care is available relatives experience a sense of security, control and comfort.

<p>Seymour, Almack, &amp; Kennedy (2010) Implementing advance care planning: a qualitative study of community nurses' views and experiences. <i>BMC palliative care</i> 9(1) 4-4.</p>	<p>To explore how community palliative care nurses understood advance care planning for patients unable to communicate wishes.</p>	<p>Qualitative study using constant comparative method.</p>	<p>23 community nurses from two cancer networks in England participated in six focus groups.</p>	<p>Advance care planning regarded as a positive intervention but a number of challenges identified including, timing of conversations, team communication, and lack of resources.</p>
<p>Tomlinson, Barker, &amp; Soden (2011) What are cancer patients' experiences and preferences for the provision of written information in the palliative care setting? A focus group study <i>Palliative Medicine</i> 26(5) 760-765.</p>	<p>To identify the impact of written information around services for patients referred to a specialist palliative care service</p>	<p>Qualitative study using a realist approach to thematic analysis</p>	<p>Five focus groups with 22 cancer patients in a specialist palliative care unit in the UK</p>	<p>Small sample size but did identify that desire for information was variable and individual. Most patients felt information was important and empowering but wished for a mix of verbal and written information that was accessible and understandable.</p>
<p>Venkatasalu et al. (2013) Talking about end-of-life care: the perspectives of older South Asians living in East London. <i>Journal of Research in Nursing</i> 18(5) 394-406.</p>	<p>Explore perspectives of older South Asians living in East London towards talking about death and dying</p>	<p>Qualitative study using constructivist grounded theory approach.</p>	<p>Fifty-five South Asian participants aged between 55-78 years took part in either 29 semi structured interviews or five focus groups.</p>	<p>Themes suggest that there is a cultural norm to avoid discussion of death and dying. Younger family members assume a decision-making role and protect older people from discussions. It is unknown whether subsequent generations will adopt a different approach to conversations.</p>

<p>Woods and Salter (2013) A time and place: what people want at end of life. Sue Ryder.</p>	<p>To explore the relationship between preferred place of death, and the outcomes people value at end of life.</p>	<p>Mixed method study in three phases including, qualitative interviews, survey and focus groups.</p>	<p>Semi structured interviews with experts in palliative and end of life care, Survey of the general population (n=2,038) and focus groups with relatives (n=9) of bereaved people from different locations.</p>	<p>Findings suggest that priorities for care at end of life focus on pain management, being with loved ones, privacy and dignity and being in familiar surroundings. Preference of care at home shifts from 91% to 63% toward hospice care at the end of life. Prior experiences shape preferences shift over the course of the illness trajectory.</p>
<p>Williams et al. (2016) 'Because it's the wife who has to look after the man': A descriptive qualitative study of older women and the intersection of gender and the provision of family caregiving at the end of life. <i>Palliative Medicine</i>.</p>	<p>To explore older women's views about the roles of women and men in providing palliative and end-of-life care for family members</p>	<p>Qualitative interpretive study using thematic analysis to explore focus group discussion around advance care planning.</p>	<p>Six focus groups conducted with 36 women aged 50-99 identified through community organisations in New Zealand. Two vignettes to prompt discussion about experience of end of life caring and attitudes towards Advance Care Planning.</p>	<p>Gendered norms and expectations inform women's caring role. Women assumed a caring role as natural and expected, despite implications for their own health and wellbeing. This paper asserts that policy should acknowledge the impact of caring on older women. .</p>

# Chapter 4: Methods & Methodology

## 4.1 Introduction

This chapter outlines the methodological expression of the epistemological stance adopted within this study; social constructionist grounded theory (SCGT). Secondly, this chapter provides an account of using SCGT in practice and includes an overview of issues arising 'in the field' specifically: ethical issues, access, data collection, and analysis. In line with SCGT, there is a strong emphasis on reflexivity, which threads throughout the research process and is present within all the chapters of this thesis.

### 4.1.2 Social Constructionism

The ontological and epistemological approach of constructionism informs the study design in exploring how people come to use hospice services and examine how individuals make sense of choice within the context of palliative care. The epistemological approach of constructionism adopted within this study is situated within an interpretive paradigm described by Denzin & Lincoln (2013, p.27) as spanning four abstract positions of positivist, constructivist-interpretive, critical realist, and feminist post structural heuristic approaches to studying the social world. Gergen (2015) traces the foundations of constructionist theory over the last thirty years, citing the work of post structuralists such as Saussure (1857-1913) and Derrida (1930-2004), and symbolic interactionists such as Mead (1863-1931), Schutz (1899-1959) and Goffman (1922-1982) as all contributing to a growing assertion that both structural and individual interactions shape constructions of reality.

Ali (2012) identifies constructionism as emerging from a semiotic tradition in which meanings and language construct ideas about the social world. This definition shares a symbolic interactionist tradition in which language is

recognized as fundamental in shaping shared understandings of the social world. Gergen (2015) similarly refers to the work of early structuralists such as Wittgenstein in exploring how language games shape interactions and understandings of reality. Ashworth (1979, p.14) in an early exposition of symbolic interactionism, pulls on the theories of Mead and Schutz in exploring how symbols and language create what Schutz describes as an 'intersubjectivity', in which individuals experience a commonality of understandings around 'taken for grantedness', described as a 'reciprocity of perspectives'. Berger and Luckmann's (1966) work 'The social construction of reality' in 1966, (Gergen 2015p. 24) explores 'plausibility structures' in which every-day and commonsense structures shape individual understandings of, and responses to, the social world. Gergen (2015) argues that the cultural and theoretical shifts toward language and meaning occurred at a turning point in science stimulated by Kuhn's seminal work on paradigms that challenged positivist approaches as to the nature of reality within social science.

Within the context of health and illness, Conrad and Barker (2010) argue that constructionist approaches draw on the theoretical influences of phenomenology and symbolic interactionism and highlight that action is not neutral but experienced within a social and cultural context. It can be argued that this perspective has its foundations in the work of Foucault and genealogy (1973,1980) in exploring how power and knowledge became a form of cultural discipline and control in the 'medical gaze'. In this tradition, Conrad & Barker (2010) argue that the social constructionism of health and illness allows a contemporary understanding of health on three levels. Firstly, constructionist approaches enable an exploration of how society responds to health and illness; secondly, constructionist approaches examine individual experience of living and managing illness, and thirdly, it is argued that as health and illness are not merely medical and biological facts, but are instead constructs, and as such open to contestation. Central to the constructionist argument is the possibility that meanings are fluid and therefore a constructionist ontology accepts the possibility of multiple realities in a subjective epistemology (Denzin & Lincoln 2013). Both Gergen (2015) and Charmaz (2013, p. 297) particularly focus on constructionist approaches as a form of contestation which enables an

exploration of discourses, positions and meanings and provides deeper understanding of how discourses may subjugate individuals or groups and therefore enables the potential for new meanings or ways of seeing to emerge.

A constructionist approach focusing on perceptions of palliative care, meanings and discourse in the context of death and dying is particularly salient given the lineage of social constructionism within palliative care research. The seminal work of Seale (1998) and notions of the good death (see for example, Howarth 2007, Stiel et al. 2010, and Borgstrom, 2014) indicate that constructions of death, dying and palliative care shape how end of life and palliative care is experienced and understood. In my professional practice, how people came to use hospice services, referral processes, particularly referral criteria were unclear. In my own personal experience, mixed decisions around accessing hospice care were shaped by assumptions from both my parents and the professionals involved in their care, all reflecting wider societal attitudes toward death, dying, hope and care. Against this background it would seem that notions of choice at end of life, and understandings of hospice care, appear to be socially mediated and conceptualised against an array of competing (professional, lay, structural) understandings of death and dying. An exploration of how people come to access hospice services and the negotiation of 'choice' would seem to require an understanding of the constructs and interactions that interplay around palliative care and choice. A constructionist epistemological standpoint informs Charmaz's approach to grounded theory. Social constructivist grounded theory (SCGT) therefore presents as a 'fit' in the understandings of death and dying as socially constructed.

### **4.1.3 Grounded Theory**

Charmaz (2000 p.511) cites that Glaser & Strauss developed grounded theory in response to a positivist paradigm dominant within social research in the 1960s. Grounded theory has 'evolved' so that, even within grounded theory there are a number of approaches with different epistemological perspectives, reflecting in part the 'methodological pluralism' emerging within the social

sciences generally (Gibson & Hartman 2014). Early formulations of grounded theory (chiefly Glaser & Strauss) are described as having positivist leanings, with later grounded theorists learning toward a situational post-modern approach (Clarke 2005, Gibson & Hartman 2014).

Terminology within the different approaches to grounded theory (classic grounded theory, constructivist grounded theory, situational analysis for example) can be confusing (Bryant & Charmaz 2007, Mruck & May 2007). However, despite differences, there are common characteristics. Table 5, (adapted from the work of Flick (2014, p. 398), and Hutchison et al. (2010)) presents the general underpinning principles of grounded theory.

**Table 5: Key principles of grounded theory.**

An iterative and cyclical approach	Data collection is concurrent with analysis. Early analysis informs sampling and analysis.
Constant comparison of cases and categories	Categories and cases are analysed and explored across a number of dimensions.
Theoretical sampling	Early coding informs and directs sampling and enables further clarification and exploration of codes and categories. Basing sampling on concurrent data analysis is both purposive and theoretical.
Theoretical saturation of categories	Theoretical density of analysis involving clarification and exploration of categories. Charmaz (2006) and Flick (2014) argue that theoretical saturation is complete, not when interviewees present similar stories or when no new codes are 'discovered' within the interviews, but when the dimensions of key core categories have been sufficiently explored for variance, temporality and process in order to support theory development.
Theory is developed inductively from the data	Theory grounded in the data, through a process of open coding, axial or focused coding, memo writing, and reflexivity.
Codes are grounded in the data, rather than forced or imposed upon the data	Codes explored for patterns, and variation (described by Glaser 2002 and Holton 2007 as searching for 'latent patterns'). Patterns and groupings identified in open coding form categories. Coding 'raises' categories from the data so that theory remains grounded in the data.
Aims for theory which is	Evidence for depth and density of analysis. Memos,

analytical, and grounded in the data rather than a descriptive account	reflexivity, sampling provide transparency, and depth to the analytical process
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Glaser & Strauss in the 'Discovery of Grounded Theory' (1967) first outlined grounded theory in their collaborative work on 'Awareness of Dying' (1965). Bryant & Charmaz (2007) and Ward et al. (2015) suggest that the development of 'classic' grounded theory was a response to the positioning of qualitative research as unsystematic and descriptive. Paradoxically however, Bryant & Charmaz (2007) argue that key features of classic grounded theory, specifically the idea of theory emerging through a procedural approach in which researchers act as objective and removed observers reflects a positivist and objectivist dominance to exploring the social world:

*“As a consequence the popularity of GTM (grounded theory method) is double-edged. In its early formulations, it provided a justification for doing qualitative research, but it did so initially by imposing a positivist mantle on that process”* (Bryman & Charmaz 2007, p.48).

Later developments in grounded theory emerge most notably through the work of Strauss and Corbin within the Chicago School of Sociology cite the influence of symbolic interactionism and theorists such as Garfinkel, Goffman, and Berger & Luckmann. Symbolic interactionism focuses on meaning, actions, and processes and is described as being highly compatible with a grounded theory focus on action, process, and context (Bryant & Charmaz 2007, Charmaz 2014)

#### **4.1.4 Social Constructivist Grounded Theory (SCGT)**

Charmaz, a student of Strauss and Corbin, has become the leading proponent of a social constructivist approach to grounded theory (SCGT) (Mills, et al. 2006, Ward et al. 2015). Charmaz acknowledges the symbolic interactionist underpinnings of grounded theory, describing an emphasis on the role of language and social interaction but also emphasises that social relations create a dynamic shaping of the social world (2014, Charmaz & Belgrave 2012).

Charmaz's stance is clear that constructionism within grounded theory explores the relational dynamics of the social world, but also acknowledges research activity as a social practice, in which the researcher is a key actor (Charmaz 2008, 2014). This approach combines the interactionist perspective of Strauss and Corbin but also 'integrates relativity and reflexivity throughout the research process' (Charmaz 2013, p. 303).

A number of theorists argue that Charmaz uses the terms constructivism and constructionism interchangeably (see Charmaz, 2008, 2013 and Ward, 2015). However, Gergen (2015), Andrews (2012), and Ward et al. (2015) suggest that the difference between terms is one of emphasis. Constructivism is associated with Vygotskian theories of language and learning (Ward et al 2015) and focus on how language and experience shape individual understandings. In contrast, constructionism focuses more on the social cultural context of interactions and the relational practices that shape perceptions of reality. In this way, knowledge is 'constructed and reconstructed via discourse' (Ward et al 2015, p.6). In her later work Charmaz (2014) clarifies her position regarding constructivism and constructionism, arguing that constructivism acknowledges that knowing is a subjective construction between the researcher and the researched. Charmaz's approach to social constructivist grounded theory focusses on individual perceptions but is also grounded in the relational dynamics of the social world (Charmaz 2008) particularly in how and why 'participants construct meanings in specific situations' (Charmaz 2014, p.239). Charmaz therefore positions Social Constructivist Grounded Theory (SCGT) within social constructionist approaches to understanding the social world, writing that:

*"Consistent with Marx, I assume that people make their worlds but do not make them as they please. Rather, worlds are constructed under particular historical and social conditions that shape our views, actions, and collective practices."* (Charmaz 2008, p.13).

Hutchison et al. (2010) and Charmaz (2014) argue that SCGT offers a flexible approach. However, Charmaz counters claims that such flexibility is relativist in that it undermines authenticity or theory generation. Charmaz (2006, 2014)

argues that social constructivist grounded theory (SCGT) is an inductive approach, which does not impose pre-existing frameworks on data analysis but is instead grounded in the data. Charmaz (2013) argues that rather than assuming an objectivist truth to be discovered, SCGT emphasises that theory is co constructed, and that any analysis is 'contextually situated in time, place culture and situation' (2006, p.130), exposing preconceived understandings and enabling unheard voices to be heard. Recognition of SCGT as a relational and interpretive approach requires a reflexive approach to social research (Charmaz, 2008, p. 524; Mills 2006). Reflexivity, a process in which the researcher is sensitive to his or her own role in interpreting and constructing theory is therefore foregrounded throughout the SCGT approach. Table 6, based on the work of Flick (2014), Hutchison et al. (2010), Gibson & Hartman (2014, p.61) and Charmaz (2013, 2014) provides a summary of the key principles of SCGT methodology

Table 6: Principles of SCGT Methodology.

Key Approach	Implications
Reflexive	<p>Emphasises reflexivity throughout the research process.</p> <p>Research is a negotiated process.</p> <p>Considers the positionality of the researcher and participants.</p> <p>Acknowledges subjectivity throughout the data analysis.</p>
Interpretive	<p>SCGT rejects objectivity and assumes multiple realities.</p> <p>Interpretive understanding of data.</p> <p>Focusses on everyday meaning and use of constructs.</p> <p>(Re) presents participants' views and voices as central to the analysis.</p>
Co-generation of theory	<p>Emphasises co-generation of theory in the discovery of meaningful constructs.</p> <p>Explores concepts such as power, privilege and equity.</p> <p>Generalisations are partial, conditional and situated in time, space and positions, actions</p>

	<p>and interactions.</p> <p>Aims to generate theory, which has credibility, originality, resonance and usefulness.</p>
Research process	<p>Considers variation and difference.</p> <p>Meaningful constructs developed from critically defined categories situated within the meanings of participants.</p> <p>The research process is interpretive and flexible.</p> <p>Emphasises reflexivity.</p>

## 4.2 SCGT as method

There are however, features around reflexivity, memoing, and focused coding which differentiate SCGT from other grounded theory methods, as outlined below:

### 4.2.1 Reflexivity in SCGT

Urquhart (2013) argues that a ‘tabula rasa’ (blank slate) is required for all grounded theory approaches, and signifies not a discounting of knowledge, but an avoidance of ‘forcing’ preconceptions on to the analytical process. Charmaz (2008, 2006) however, argues for an overt and explicit acknowledgement of the researcher’s role in co construction and that, “rather than being tabula rasa, constructionists advocate recognising prior knowledge and theoretical preconceptions, and subjecting them to rigorous scrutiny” (Charmaz 2008, p.402).

Bourdieu (Maton 2003) was influential in recognising the role of reflexivity (a process of acute critical self-reflection) within qualitative approaches to research. Rather than objectify the researched and demand a process of bracketing, SCGT advocates reflexivity as a form of self-critical awareness of the researcher’s role in constructing the final research product. Reflexivity enables an inductive approach to ‘hearing’ the voices of others, (Charmaz 2006) whilst also recognising the researcher’s role in interpreting the story told.

This requires less a Husserlian 'bracketing' of a priori knowledge, and more an acknowledgement of how a priori knowledge might shape the research process. There is a tension articulated by Maton (2003) in that reflexivity can present as a narcissistic focus on the researcher, rather than the research topic. However, the positioning of the researcher is fundamental to the research process, and is integral in influencing the relationship between researched and researcher, particularly around issues of access, interviews, and analysis, and indeed the research question at the outset.

#### **4.2.2 Memos in SCGT**

A feature of grounded theory generally is the use of memos in facilitating analysis. Memos are described by Gibson & Hartman (2014, p.182) as the 'most operational aspect of grounded theory' whilst Lempert (2007) argues that memos are to be considered as complex tools, as they not only describe but also conceptualise data. There are different types of memos, serving different purposes, for example, Montgomery & Bailey (2007) include field notes, descriptive research reflections, and theoretical memos as forms of memos citing that these together inform analytical thinking. Birks, Chapman & Frances (2008) agree that memoing in SCGT is a flexible process, given that interpretation is a creative process (Mills, Bonner, & Francis (2006). In SCGT Charmaz (2006) specifically advocates memo writing early when adopting a SCGT approach arguing that this will facilitate early engagement with analysis, contributing to what she describes as 'intellectual capital in the bank'. Importantly, Charmaz (2006) is also clear that memos not only aid the writing of the project, but also importantly serve to explore how categories are rendered and generated, ensuring that analysis is grounded in data, rather than 'emerging'. Finally, Charmaz (2006, p.94) concurs that memos provide a transparent record of progress and analytic thinking.

### **4.2.3 SCGT and Focused Coding**

Most grounded theory studies including SCGT begin with open coding; a line-by-line approach to look for patterns within the data (described by Glazer (2002) as searching for latent patterns). This initial coding leads to the grouping of sub-categories, which underpin core categories through a further level of coding described by Charmaz in SCGT as focused coding. This approach provides a contrast to both axial coding (using a coding frame of conditions, actions, and consequences) as advocated by Strauss and Corbin, (Flick 2014, Charmaz 2006), and theoretical coding (enabling theory to emerge) as advocated within Glaser's approach to grounded theory. Charmaz does not entirely reject alternative approaches to coding (Gibson & Hartman 2014) but instead argues that focused coding offers a means of identifying frequent or significant codes, and exploring more deeply in terms of action, process and meaning. Gibson & Hartman (2014) identify that Charmaz emphasizes the use of gerunds (verbs capturing action) more so than other grounded theory approaches, as a means of foregrounding the action in meaning. Charmaz (2006) argues that this approach offers a less procedural means for exploring data (Charmaz 2006) and avoids 'forcing' a procedural framework on to the data (described as an 'over complication' by Gibson & Hartman 2014), thereby ensuring that analysis remains grounded in the data. Charmaz argues that this approach avoids asserting that theory 'emerges' objectively from the data, and instead enables a relational and co constructivist approach to analysis (Charmaz 2008).

The above provides an overview of the methodological considerations of 'doing' grounded theory. The following section provides an overview of using SCGT in the 'real' world setting. The following will outline the research design adopted in the study, and will reflexively explore each facet of the research process in practice.

### **4.3. Methodology in practice**

Ward (2015) suggests that research within a palliative care context raises a number of potential challenges, and this study was no exception. Issues cited by Ward (2015) and Payne et al. (2013) are in some ways overlapping and include factors around gatekeeping, the highly sensitive and emotional intensity of end of life, ethical issues and access, many of which were also evident in the current study, and which required a re-evaluation of the study design. 'Doing' research (Robson 2016, Bate 2007) requires reflexivity and the ability to think creatively around detailing a design and this remains a challenging aspect of the research process. The following outlines how the study design was shaped by a series of pragmatic and ethical responses to researching in a palliative care setting, and presents a reflective account of the study, supported by data from the reflective diary and field notes.

#### **4.3.1 Research setting**

The following provides an overview of the research setting. In this study, I aimed to explore how people came to use hospice services, and how decisions around access and care were understood, and negotiated between service users and service providers. For some years, I worked as a part-time staff nurse on the in-patient unit of a UK based inner city hospice. Hospices occupy an independent position within the health care arena and are often responsive to local issues, leading to local variation in service delivery (Payne et al. 2013). The city has two palliative care units, (a hospice and a hospital in-patient unit) and provides care to a large population of over 551,800, in what is the third largest metropolitan authority. Nineteen per cent of the population consists of a range of black and ethnic minority groups.<sup>2</sup> Both units collaborate but funding patterns differ, with the hospice being only partly NHS funded. The palliative care unit resides within the hospital complex and forms part of the hospital trust. The research study however, focused on the hospice, located separately on the other side of the city.

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<sup>2</sup> (Sheffield City Council 2017 <https://www.sheffield.gov.uk/home/your-city-council/population-in-sheffield>).

The hospice was one of the first hospices to be located outside of London (Noble & Winslow 2015) and has occupied the current site for over 45 years. During this period, it has expanded and the current hospice trustee report cites that for 2015-2016 the hospice provided care to over 1600 adult patients (over 18 years) and families and provides palliative care for a broad range of conditions including cancer, and neurological conditions. At the time of the study, three sectors provided services including the inpatient unit, the Therapy & Rehabilitation Day Unit (TRU) and the community setting (Hospice Trustees Report 2015-2016). The hospice also provided support to carers and provided ongoing bereavement support.

There were four management leads including the chief executive; the deputy chief executive and director of patient services; a medical director (also with responsibility for research and clinical governance) and a director of finance and operations. A lead nurse managed the Community and Therapy & Rehabilitation Day Unit, a ward nurse manager led the inpatient unit and a lead social worker managed the allied health services (social work, complementary therapists, and bereavement counselling service). There was also a large volunteer workforce contributing to fundraising, as well as the day-to-day work of the hospice.

The therapies and rehabilitation centre (TRC) offered a rolling programme of day support to patients, providing a range of interventions including; medical support; physiotherapy; occupational therapy as well as complementary therapy, and remains a nurse led unit. Patients usually attended for one day per week over approximately six weeks (depending on assessment and condition). Referral was from a range of services including self-referral, General Practitioner (GP), acute hospital services (particularly oncology), and community teams. The centre also provided bereavement and spiritual care and a weekly carers group.

### 4.3.2 Study design

The study aimed to explore choice and decision-making around access to hospice services through the perspectives of palliative care patients, carers and clinical staff. A qualitative approach underpinned by SCGT informed the study design. Yin (2014) and Flick (2014) suggest that a case study presents a clear focused approach to exploring particular features of a case, community or organisation. However, the intention of this study was to explore understandings of choice and decision-making around hospice care generally, rather than how such processes related to a particular hospice. The study design did not therefore propose a case study approach. Initially, I proposed inviting patients receiving hospice community services or attending the day therapy and rehabilitation Centre (TRC) (who might be earlier in their disease trajectory and able to contemplate care decisions) to take part in semi-structured one-to-one interviews in order to relate their experiences of how they came to use the hospice services.

Using the NICE (2004) definition of carer (see Chapter 3), patient participants were also to invite their 'carer', identified as the person who provided them with most support, to participate in a further one-to-one interview. This would provide a dyad. Patient participants would also identify the health professional most involved in supporting care (which was presumed to be either one of the hospice community nurses or one of the day hospice nurses), to participate in a one-to-one interview to discuss reflections on choice and decision-making generally and in relation to the patient participant. The aim was to triangulate patient and carer and staff perspectives (Flick 2014).

Triangulation of the three perspectives (carer, patient, and staff), offers a means of exploring insights beyond one perspective and can potentially add quality to the research product (Flick 2014, p.184). This echoes the work of Adami & Kiger (2005) who argue that triangulation provides a complete and contextual interpretation of the research question. This study aimed to explore triangulation of data source (patients, staff and carers) and the constant, comparative and iterative approach of SCGT complements the analysis of

different perspectives. Flick (2014) cautions however that, although triangulation may give a fuller vision, this is not a form of validation, and such a view would support the constructionist principles within this study in that 'different readings' may render different but equally valid truths.

The University of Sheffield Palliative Care Studies Advisory Group provided a service user perspective on the proposed study design, particularly around an approach using Pictor and the sensitivity and appropriateness of the semi-structured interview schedules. It is recognised that research imposes a positioning of power relations in which the researcher is supported by institutional and educational structures and the researched are less involved in shaping data, findings and outputs (Birch & Miller, 2002, p.111). There is therefore an emphasis on public and patient involvement guiding the research process (see for example, Popay & Collins 2014 and the National Institute for Health Research: INVOLVE 2017). The contribution of the service user advisory group was congruent with the principles of SCGT and co-construction, and I particularly valued the advice of the group in how best to work with Pictor in interviewing participants (see 4.5.2).

The initial Phase One literature review (see Chapter three) informed the first draft of the proposed semi-structured interview schedules and aimed to guide discussions around perceptions of hospice care, experience of access, carer support, hospice and self-identity, and reflections on information giving and understandings. SCGT is a flexible approach to interviewing given the iterative process of analysis and interviewing, however, a preliminary interview guide is helpful at the start of data collection. Participants were to include patients supported by the hospice community services, carers identified by patients, and staff identified as supporting care and care decisions. Interviews were to be audio-recorded and visual materials retained for further analysis. The study design also aimed to utilise a Pictor style approach within interviews.

Pictor is an approach in which participants document key points or key words on post-it® notes and placed on a blank piece of paper. Participants review their post-it® notes at the close of the interview, rearranging as they recap on

the interview. Hardy (2011) and Wilson et al. (2011) advocate the use of pictorial techniques, such as visual mapping to help participants relay their stories and reflect on key turning points. Pictor has been successfully used within a number of palliative care studies by King et al. (2010, 2013), and Hardy et al. (2011), as a visual approach using post-it® notes within qualitative interviews. This approach complements the tradition of diagramming and mapping within grounded theory and situational analysis (Charmaz 2006, Clarke 2005). Using visual reflection with participants also complements the emphasis within SCGT on co construction (Charmaz 2008). A palliative care advisory group of service users agreed to ‘pilot test’ using Pictor as a tool for facilitating interviews with positive feedback. The response to the technique was positive, and the approach incorporated into the study design.

One of the study aims was to explore issues of ethnicity in shaping access and decisions to access hospice services. I arranged for the translation of study packs including information sheets and consent forms into Urdu in order to facilitate participant perspectives from the local Asian population. Figure 3 provides an overview of the proposed design.

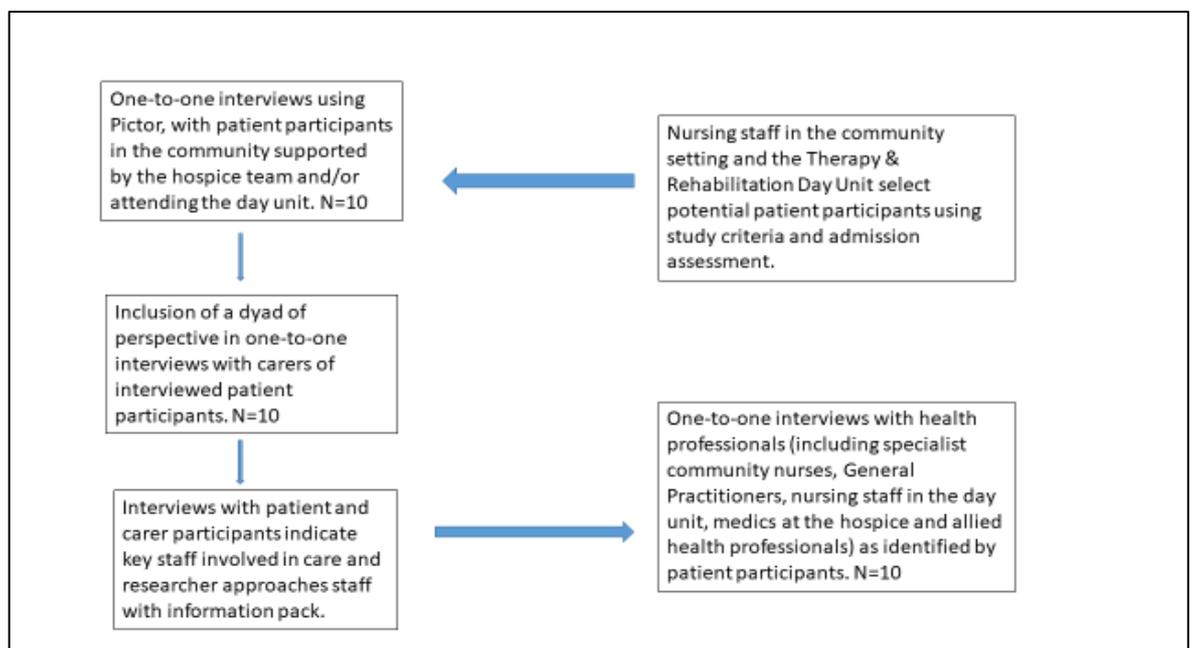


Figure 3: Overview of proposed design.

The practicalities of researching within a clinical setting particularly in terms of access however required a review of the study design (see section 4.4.1 for further detail on recruiting participants). Despite the community nursing team having study packs, they were unable to recruit patient participants. The community nursing team identified that community patients had high palliative care needs, and therefore did not meet the study criteria as they were deemed too ill to participate. Recruitment of patient participants therefore focused on the Therapy and Rehabilitation Unit (TRU). With regard to interviewing staff, most patient participants were generally unable to identify a particular staff member central to their decision to accept hospice care. Following discussion with the management team, I was able to invite staff to take part in either focus group or in one-to-one interviews staff who were *generally* involved in referral decisions or supporting care, rather than specifically associated with a particular patient. The challenges of involving carers in research are well-documented (Grande et al. 2009, Payne & Morbey, 2013) and patient participants were reluctant to involve their carer/relative in the study, often expressing concerns over burden. I was unable to recruit more than one patient/carer dyad. However, after consulting with the hospice management team, I was able to present the study to a small number of carers attending the hospice carers support group, some of whom agreed to take part in an interview. A revised study design also reflects that some patient participants identified staff from the local oncology unit as well as General Practitioners (GPs) in their care. The study design in practice therefore captures the pragmatics of researching in practice. Figure 4. illustrates the study design in practice.

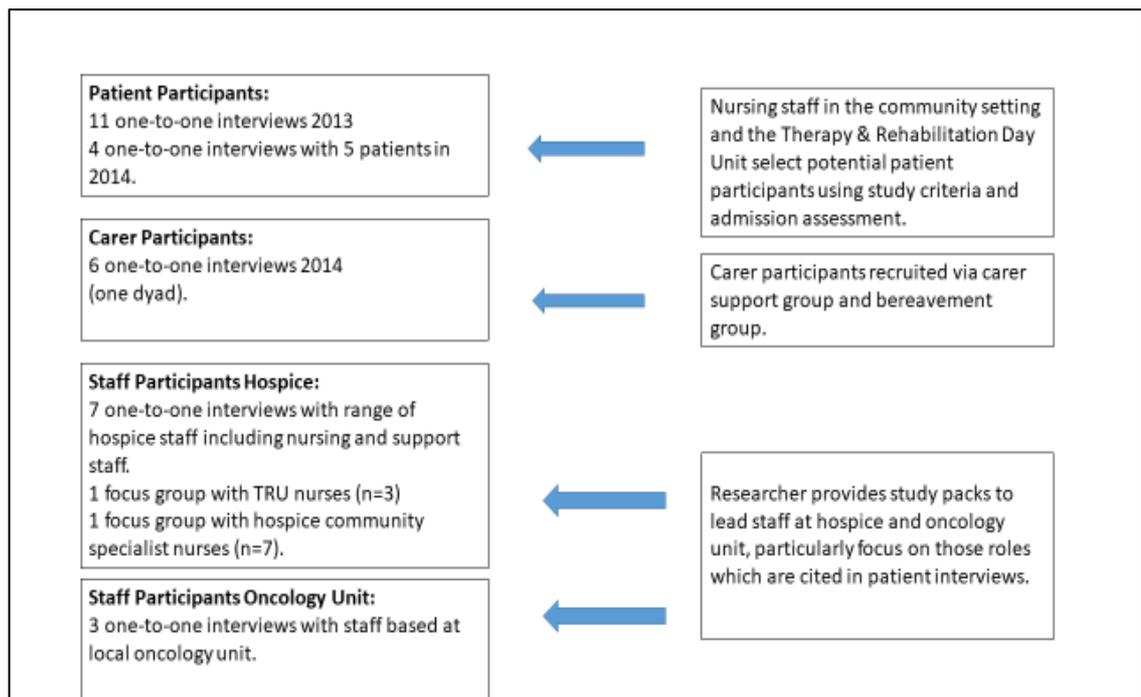


Figure 4: Study design in practice

In total, fifteen patient participants took part in the study along with six carers (providing one patient/carer dyad) and twenty staff participants (including nursing, medical and support staff). All provided one-to-one interviews apart from ten nursing staff participants who took part in two focus groups (n=3, and n=7). Chapters five, six and seven provide a demographic profile.

#### 4.3.3 Ethical considerations:

Seeking NHS ethical approval is complex within the hospice setting and end of life care research is often regarded as highly sensitive (Campbell et al. 2016). Some of the challenges reside in researching qualitatively within an ethical framework of governance established primarily for clinical trials. Further complications lie with the uncertain NHS status of hospice settings, which are only part NHS, and are often small organisations with limited research governance structures (Payne et al. 2013). Nevertheless, ethical review is an essential process, and particularly useful in honing the study design to ensure that ethical principles were in place.

The Integrated Research Application System (IRAS) provided the portal for submission of the proposed study for ethical scrutiny and I presented before the local NHS ethics committee and the local hospice management team. I was concerned that a qualitative approach would not ‘fit’ a medical ethics committee familiar with quantitative approaches, but the review was supportive. The NHS medical ethics committee approved the study (REC number 12/YH/0291 see Appendix 7 and 8) following minor amendments (for example, a request that the term ‘risk’ be removed from the study materials, as this might cause unease in participants, and a recommendation that professional interpreters must be utilised for non-English speaking interpreters).

The University of Sheffield also provided sponsorship and insurance indemnity (see Appendix 9) and the study registered on the University Research Management System (URMS). In line with theoretical sampling, an ethics amendment was required to seek approval to access staff in the local oncology unit in order to interview a small number of referring staff and this amendment was approved in a second submission (see Appendix 8). Table 7 provides a timeline detailing this lengthy but necessary procedure.

Table 7: Timeline documenting ethical approvals.

<b>Time Frame</b>	<b>Procedure</b>
27-02- 2012	Draft of Integrated Research Application submission discussed with community lead nurse around appropriateness of recruitment strategy and information sheets. Correspondence with Primary Care Trust regarding provision of research and development (R & D) governance as question mark over whether NHS governance should be provided by the hospice (only part NHS) or by the primary care trust.
18-01-2012	Meet hospice Service User Facilitator to discuss ethics submission, particularly in ensuring information sheets appropriate for service user perspectives. Presentation with service users of the UoS Palliative Care Advisory Group to discuss the study, particularly around the study design and information sheets to provide a service user perspective. Four agree to provide a pilot interview.
18-4-2012	Hospice lead for clinical governance agrees to act as R& D in supporting NHS ethics submission.
02-07-2012	Attend Ethics Committee
13-07-2012	Ethics granted (see Appendix 7 for letter of approval) with minor revisions, chiefly around avoiding the word ‘risk’ around decision-making in information materials. Requests the use of professional interpreters in interviews with non-English speaking participants and translation of study information materials into Urdu.
05-11-2012	Insurance indemnity from University of Sheffield (UoS). See Appendix 9. Authorisation of UoS sponsorship.

	Register on URMS
10-07-2014	Ethics amendment requested in order to access oncology unit for staff and GPs from GP forum with links to the hospice. See Appendix 8.
21-9-2014	In line with theoretical sampling, the study recruits staff from the local oncology unit. Ethics amendment granted from NHS committee, and research passport, letter of access, teaching hospitals approval and honorary contract granted from the hospital trust. Presentation at Oncology Unit Clinical Trials meeting.

A mix of moral, legal and professional frameworks shape ethical considerations at both a macro and micro level and serve to underpin the entire research process from study design to dissemination (Ali & Kelly 2012). Childress & Beauchamp (2001) provide a commonly used ethical framework around the principles of maleficence, beneficence, autonomy and fairness, and this informed the ethical principles of this study. The British Sociological Association (BSA 2017), Royal College of Nursing (RCN: 2011) and the Health Research Authority (2017) and University of Sheffield Research & Innovation department (2017) provide guidance on research governance including guidelines around the responsibilities of researchers. The key principle underpinning all is one of informed consent.

Informed consent requires clear unambiguous information and should be presented in formats which allow individuals to access the information, deliberate (and include friends and relatives in discussion) and respond, with options to withdraw at any time (RCN, 2011). Oakley (2000) identifies that a formal process of informed consent at one point does not necessarily ensure that participants fully understand their rights nor the study. Indeed, Sanjari et al. (2014) argue that informed consent around anonymity and confidentiality can mean different things to different people. Consent is therefore a negotiated and ongoing activity throughout the research process (Sociological Association BSA 2017; Miller & Bell 2002). I was very keen that the consent process was not coercive, with opportunities for participants to withdraw from the study at any point, but also ensuring a period of at least a week between information giving and consenting to participate. I was unsure whether participants would assume that they were supporting the work of the hospice and so I was keen to ensure that my role was clear to participants, and emphasised that I was a student at the university rather than a nurse at the hospice.

Pleschberger et al. (2011) discuss the unpredictability and potentially emotional implications of qualitative interviews and I was aware of the possibility for distress. Mason (2002, p. 79) recommends that whilst difficult to predict, researchers should attend to the possibility that unforeseen issues may arise within the interview process in order to act in a 'ethically principled way'. As a nurse and a researcher, I had a dual responsibility to manage distress whilst at the same time balance a compromise between ethical standards of confidentiality and to do no harm. In this study, I devised, with advice from other researchers and the management team, a process for managing distress that considered issues of confidentiality and the potential for harm. A list of local and national support contacts (see Appendix 10a), was provided for participants should they feel they required follow up support. Where any issues requiring medical or nursing support were apparent during the interviews, then following discussion and, importantly, permission from the interviewee, I would notify the relevant clinical staff. The need to follow this process occurred in two incidents involving carers (discussed in detail in section 8). Although interviews were sometimes emotional due to the nature of the subject, none wished to stop the interviews or withdraw from the study, and none took the offered support contacts list. The responses reflect the work of Gysels et al. (2013) that participants facing end of life can regard qualitative interviews as positive intervention and a means of offering their experiences to help others.

#### **4.3.4 Ethical issues 'in the field'**

Micro ethical issues refer to issues of trustworthiness, and integrity in the practice of 'doing' research. Charmaz (2006) argues that SCGT acts as a form of social justice in giving voice to the seldom-heard. Duncombe & Jessop (2002) however, provide an overview of the complexity and uneasy tensions around 'doing research' and 'doing rapport'. Whilst rapport and building relationships with participants is central to qualitative research, this has potential to be exploitative and for agendas to be misunderstood. Clarke (2005) and Allmark et al. (2009) argue that researchers need to be mindful and

reflexive, echoing Kvale (2007, p.31) that the researcher has to use moral integrity to inform and make 'on the spot' decisions around ethical practice.

Two examples of unanticipated ethical dilemmas provide an insight into the challenges of researching in end of life care and the need to balance ethical procedure (macro ethics) against personal integrity (micro ethics) 'in the field'. Husband and wife Carer C01 and Patient Participant P02, were the only patient and carer dyad in the study. The couple took part in separate interviews, (she attended the day hospice and he was unable to stay for the interview but agreed to a later interview). The information sheet and our preliminary discussion indicated that recordings would be confidential, transcripts anonymised and recordings destroyed at the close of the study. However, following his wife's death a few months later, he started to phone me regularly and in great distress. Every call ended with his request to have a copy of his wife's recording, as he had no audio or video material, and had a desperate need to hear her voice. As confidentiality is a prime feature of ethical practice, I explained this was not possible, but his anguish was palpable. I sought advice from the IRAS ethics committee, and researchers in the local NHS trust as well as the hospice bereavement counsellor. The bereavement counsellor indicated that an extract from the recording was unlikely to cause him further distress, could possibly be therapeutic, and suggested that it might be ethical to support his wishes (see Appendix 14). An edited version (using audacity software) containing only her family stories (which were likely to be well known to the family) was given to him during the bereavement counselling session, with the offer of having someone present as he listened. He later wrote and thanked me and reported finding great reassurance in having her voice. This instance illustrates the need for researcher reflexivity in the need to balance ethics procedures against a human response to distress.

A further dilemma involved a carer who contacted me to organise an interview at the hospice. Her story began but as we talked, I realised that her mother had died only two days before. I did ask her if she wished to carry on, but she was very keen to talk. The community nurse involved in her mother's care expressed concern however following the interview, and so with the carer's

permission, I had notified the hospice bereavement counsellors. Their advice was that she had clearly made a decision to talk to someone, and as bereavement counselling would not be offered until six weeks post bereavement as per protocol, perhaps the interview had served a purpose. They did agree to follow up immediately however, and reported that she had wanted to 'give something back' by providing her experiences. Such experiences indicate the challenges of anticipating distress whilst at the same time avoiding a paternalistic approach.

#### **4.3.5 Confidentiality:**

Issues of confidentiality are paramount in protecting individuals from unforeseen harm. The researcher must be clear that information is confidential, anonymised and adheres to the Data Protection Act (Great Britain 1998). I was clear to talk through the information sheets and reiterate that I would delete audiotapes at the end of the study, and that I would remove names, and identifiers from the transcripts. However, as the work of Seymour (2001) indicates, in a small geographic area of a town, and in a small organisation, 'unwitting breaches' of confidentiality can occur. For this reason, the roles of staff, particularly those with a unique position in the services were anonymised where possible. However, despite this some individuals may be recognizable within a small organisation. This together with the nature of interviews as possible confessionals, or at least as therapeutic interventions (Kvale (2007), raises issues of participant vulnerability. This raises a further ethical dimension to 'doing' research. The BSA (2017) makes clear that dissemination is important for making research worthwhile. I would hope that readers would explore any study outputs for the potential to contribute to knowledge around palliative and end of life care, rather than as a means to identify individuals or comment on their contribution.

## 4.4 Negotiating access

Gaining access to a field site or participants is a continuous activity throughout the research process, described by Miller & Bell (2002, p.66) as a process of ethical integrity requiring negotiation of “access and reaccess”. Mulhall (2003) explores the particular challenges of negotiating access within health care settings, suggesting that researchers often access areas in which they are already known, which can set up a particular dynamic of power and pragmatics. My study raised similar issues because I had worked in the setting, both as a nurse and a link tutor. However, my decision to access the hospice rather than venture to a different setting was partly pragmatic; I was a part-time research student (with limited capacity for negotiating access elsewhere). I was also aware of the supportive research culture in the hospice.

Payne et al. (2013) argue that there is a need to develop the evidence base palliative care and call for hospices to develop a research culture. Barriers to research include organisational isolation and lack of research partnerships as well as antipathy toward research within the hospice setting. The hospice in question however, had an established culture of research with a strong association with the University. Indeed, the Sheffield Academic Unit of Supportive Care, which supports education and research in palliative care was situated within the hospice itself, and the hospice had been involved in a number of large research projects. The hospice team also acknowledged the supervisory team as renowned experts within the field of palliative care research.

I sought access to research at the hospice via the senior management team. Later interviews with patients indicated that the perspectives of staff from the local oncology unit would provide further insights. This required further negotiation to access the local oncology unit. In 2014, I approached the local oncology unit through links with a research specialist nurse at the hospital trust. The time line (see Table 8 below) from access to completion of data collection, covers three years and reflects in some way the tenacity required to negotiate and renegotiate within a ‘live’ healthcare setting, as well as the difficulties of

recruiting participants within end of life care. Nevertheless, the management team and key leads were supportive throughout.

Table 8: Timeline: negotiating access to study sites.

<b>Time Frame</b>	<b>Negotiating access to field sites</b>
08-12-2011	Meeting with Chief Executive to discuss access. Positive response but a number of projects taking place across the hospice site. Referred to Deputy Chief Executive who advises to aim to start fieldwork in February or March 2012. Suggests community setting would provide a better starting point as a number of research activities were already underway in the therapies and rehabilitation (TRC) day unit.
18-01-2012	Discussions with lead nurse to discuss practical and ethical considerations in gaining access to staff and patients within the hospice community service.
02-02-2013	Study presented to weekly specialist hospice community nurses team meeting. Staff were positive in supporting the study, and expressed willingness to take part in a focus group. Applied for funding for translation and interpreters
05-04-2013	40 study packs issued to community team. No patient participants recruited. Met with Lead nurse manager to discuss. Reasons provided included weather, organisational change, disease severity, patients who not meeting study criteria. Agree to spend a further four weeks liaising with team and raising profile. No participants come forward. Unable to access BAME individuals.
10-05-2013	Meeting with nursing staff from the Therapies and Rehabilitation (TRC) Nursing team. Nursing staff agree to support study.
May 2013- December 2014	Staff in TRC distribute study packs. 11 patient participants recruited but only 1 carer. Meeting with lead nurse to discuss access to carers and staff, particularly staff in the hospice social work department and general practitioners (GPs). Organizational change appears to influence recruitment of staff from social work department. Bereavement counsellors negotiate access to carers through bereavement support group but group decline. Four carers recruited via carer support group.
10-07-2014	Presentation of study provided as update to hospice management team. Enthusiastic in supporting recruitment of staff, including GPs and carers. Suggest raising profile of study through communications team.
21-9-2014	10-07-2014. Ethics amendment requested in order to access oncology unit for staff and GPs from GP forum with links to the hospice. Four staff based at the oncology unit and with a role in hospice referral interviewed. Continued efforts to access GP through a hospice link and key link in UoS research department prove unsuccessful. Lead research nurse at local oncology unit is supportive. Interview of specialist nursing staff at oncology unit commenced.
20-12-2014	Data collection complete.

#### 4.4.1 Recruiting participants

Initially, community nurses were to issue packs to patients who met the study criteria. There was also the possibility that patients from BAME groups were more likely to be cared for in the community and this was an important aspect of the design. However, there was no patient uptake of the study despite the

issuing of study packs (including those translated into Urdu). The community team and manager cited a number of reasons including organisational change, high levels of disease severity, and poor winter conditions (whereby study recruitment was not a priority for staff). Subsequent discussions with the management team recommended that I should focus on recruitment to the hospice therapy and rehabilitation day unit. Patients attending the Therapy and Rehabilitation Unit (TRU) were more likely to be relatively physically well, and to be contemplating care decisions, therefore more likely to be able to engage in a study around care decisions. Management also felt the unit would present a more appropriate setting as staff would be more readily on hand to support any potential participant distress, and I would not be vulnerable as a lone researcher. The study design therefore shifted to patients attending the day unit only.

I designed the study protocol in line with ethical and clinician guidance and proposed that nursing staff would identify patient participants using the following study criteria:

- Clinical judgement in assessing which patients would be able to discuss their experiences around the transition to palliative care as well as discuss current and future care without undue distress;
- Having capacity to understand the focus of the study;
- Not experiencing such severely debilitating symptoms that an interview would be onerous.

Nursing staff would provide, where appropriate, an information pack (including an information leaflet and a reply slip with stamped address envelope) inviting patients to take part. I approached carers and staff directly, and provided with an information pack, my contact details and a reply slip. Copies of the study flyer, information sheets for staff, patients, and carer, consent forms and reply slip are provided in Appendix 10a, 10b, 10c, 10d)

Gaining access to participants was a continually negotiated activity and issues of gatekeeping did arise (see section 4.4.4). The original design envisaged that

patient participants would identify a carer who might consider supporting the study. However, apart from one patient participant, all were reluctant, reflecting the study findings that patients were protective of those who supported them and preferred not to add further 'burden'. The management team also discussed the difficulties of accessing carers. The team advised that a bereavement support group of carers, bereaved for over one year would be a possible option, and it was felt this group would feel able to reflect retrospectively on their experiences. Such assumptions were incorrect, and the bereavement councillor provided feedback that this group did not wish to relive past experience. A support group for current carers took place within the hospice with only small attendance and the management team recommended that I meet and provide an informal presentation to the carers group, and five carers agreed to participate.

The original design proposed that patient participants would indicate the health professional most central to their care decisions. Patient interviews however, indicated that a number of staff were often involved in their care experiences. The study therefore recruited broadly rather than focussing on specific staff. Staff participants included staff nurses support staff, the volunteer drivers, community specialist nurses, and referring staff from the local oncology unit. The hospice management team were helpful in supporting the study, facilitating access to staff and providing time for staff to take part in interviews (if they wished). Patient interviews later indicated that referring oncology staff and general practitioners (GPs) were important in referral experiences, and I made efforts to recruit from these areas (see section 4.4). Unfortunately, despite efforts to engage via hospice links and various contacts, I was unable to recruit GPs within the timescale. However, a key lead from the oncology unit was supportive in facilitating access to clinical nursing staff who had a referring role within the unit.

#### **4.4.2 Sampling**

Given the pragmatics around gaining access, recruitment of patient participants, staff and carers was a mix of purposive, convenience and theoretical sampling (purposive in the sense that patient participants were recruited from the day

hospice, and convenience in the sense that access was reliant on nursing staff selection, participant availability, capacity and willingness to participate). The hospice management team felt that nursing staff, guided by the study criteria and their clinical judgement should assess which participants could participate without undue distress. Patients were therefore 'booked' to see me by the nursing staff in TRU. Williams et al. (2006) in the US context identify that hospice attendees were positive and motivated by altruism in participating in end of life care research, but also caution that researchers must be clear about their role. I was concerned that participants recruited via nursing staff might feel compelled to participate and was careful to ensure in the consent process to emphasise that the study was a student study supported by the hospice, rather than a 'hospice' study, and that non-participation would not affect care. The staff involved in recruiting did not record 'non response' (those patients approached who refused), suggesting either that few patients refused or that their judgement of who would engage positively was accurate.

Six carers were recruited, one via patient participant referral, the remainder from the carers support group. I also conducted two focus groups with staff who formed part of the nursing team at the hospice, chiefly the nurses within the day unit (n=3), and the specialist community hospice nurses (n=7). The line manager supported the focus group by allowing the interview to take place in the weekly clinical management meeting. I had concerns that this was potentially coercive but a team member assured me that the team were quite clear that they wished to support the study and expressed that they valued the opportunity to be involved. Indeed, a few weeks following the interview a couple of members suggested that they had found the group a valuable opportunity for discussion. The focus group with nurses within the day unit volunteered to take part in a focus group, however, they declined to be audiotaped, and expressed concerns around confidentiality within the organisation (see 4.5.1 below for detail regarding focus groups).

Theoretical sampling is part of an iterative cycle of analysis and exploration and is integral to SCGT approaches. Charmaz & Belgrave (2012) argue that theoretical sampling allows a more precise exploration of categories and more

'pointed' probing. Whilst I was not always able to analyse data prior to the next 'booked' interview, reflections following each interview provided an opportunity to pursue and test categories within interviews. For example, I had assumed that participants, particularly staff, would have an understanding of palliative care. However, in exploring the data, I realised this was not necessarily the case. I was able to probe staff understandings of hospice and palliative care in subsequent interviews. Theoretical sampling also guided sampling decisions. For example, patient and hospice staff accounts suggested that decisions to accept hospice care were often influenced by the local oncology unit, hence the decision to recruit staff from this location. Initial analysis of patient data using a constant comparative method also led to reflections on how and why some individuals were more active in engaging in care decisions and sought referral than others. Patient interviews P11-P15 focused on those who had made active decisions around their care. Figure 5 provides an overview of the recruitment process.

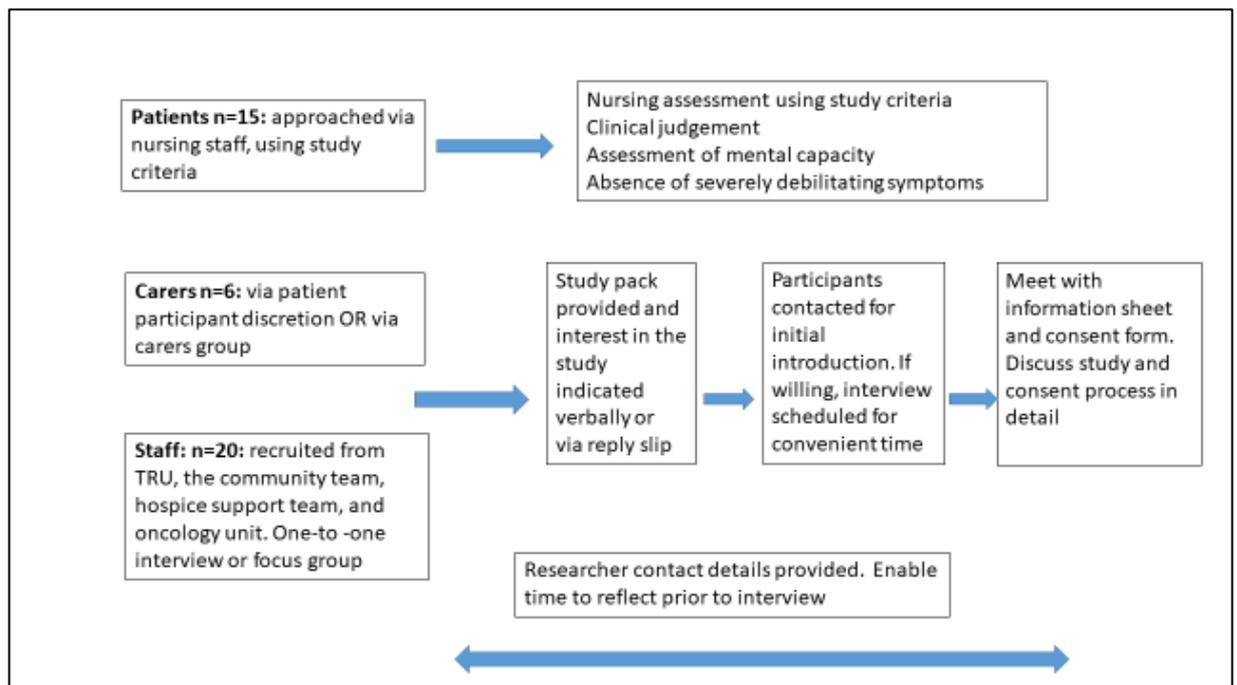


Figure 5: Recruitment process.

### **4.4.3 Accessing BAME perspectives**

One of the study aims was to explore issues of ethnicity in shaping access and decisions to access hospice services. I approached a local community interpreting service utilised by NHS community services to ensure that interpretation would meet ethical standards and that a witness statement would protect confidentiality and quality of translation. £850 funded by an existing School of Nursing study grant to translate materials and costing for interpreters was sought (see Appendix 11 and 12) for extracts from the study pack and interpreter witness statement). No members from the local BAME community came forward via the community nursing team, possibly due to lack of interest, lack of BAME presence in clinical caseload, or patients not meeting the study criteria. I was unable to recruit BAME participants via the day unit due to an absence of BAME patients attending. Nevertheless, as the study had aimed to explore issues of inequity questions around BAME access to hospice care, issues around BAME service use were explored in interviews with staff.

### **4.4.4 Gatekeeping**

Enthusiastic and research aware individuals within the staff teams were crucial in helping to support the study and access to participants. For example, the lead research nurse at the local oncology unit was positive in supporting access and negotiating research governance requirements. However, there were some occasions when access was more challenging. It is also possible that some of my experiences related to my positioning as an outsider/insider (discussed in section 8). For example, analysis of patient interviews indicated that social workers could provide a further perspective into care decisions. The lead manager responsible for this team gave permission, in principle, to approach the social work staff. However, no staff came forward in the following weeks. One of the workers was able to tell me that the project had been 'stopped'. This caused me some anxiety, but discussions with senior management indicated that the organisation supported the study and would continue to do so. I did not gain clarity as to what had happened however, and remained unable to access the social work department.

The study initially intended to recruit participants via the community specialist nursing team. However, I received no queries from potential patients and the study packs remained in the office. Staff reasons were unclear but informal discussions with the community team suggested unease in supporting access, with a suggestion that workloads were busy, (there was significant reorganisation) and that changes to service provision resulted in very sick patients within the community who did not meet the criteria. A number of studies have commented on the potential for a paternalistic attitude by staff in 'protecting' patients and carers from undue distress (Gysels et al.2008; Campbell 2016; Addington-Hall 2007; Payne 2013; Ward 2015). This possibly reflects that research has traditionally had a low profile within hospice clinical practice Payne et al. (2013), whilst Bullen et al. (2014) acknowledge time constraints are an inhibiting factor in the clinical setting. It was clear that the community staff and social work staff were undergoing significant reorganisation at the time of data collection, and capacity to support research was possibly limited, particularly as another study was also underway. The study findings also indicate that staff work hard to build relationships with patients and families. It is likely that professionals are uneasy in acting as study recruiters, preferring to focus on their clinical role and current workload.

The day unit team knew of me a little more than the community staff as I had worked with them on occasions, and following a quiet shift I visited the staff. They began to ask me questions around what a doctoral study entailed and who was paying me. I explained my interest following my mother's death some years earlier and that I was studying in my own time and contributing substantially to the course fees. This caused some amazement. From that point, nursing staff were supportive and enabling of the study. The following week one of the nurses called as she had issued a number of study packs to potential participants. Gradually the team began to work to 'help me get the study done', booking patients into interviews which fitted in with the unit routine.

Patients themselves provided further gatekeeping as all but one declined to involve the family member providing support, understandably given the sense of

loss and sadness within the interviews, and the role that many patients identified as having in supporting and protecting carers.

## **4.5 Data collection: interviews**

Qualitative interviews are often regarded as possibly therapeutic or at the very least benign in nature but both the RCN (2011), BSA (2017) and various authors (Edwards & Mauthner. 2002; Mason, 2002; Silverman, 2000; Elliott 2005 and Allmark et al, 2009) recognise that interviews require reflection, disclosure and may have very personal, unanticipated consequences for both participants and researchers. There is also some tension in qualitative research that the interview is a means of entering the 'heartlands' almost as a counselling session, and although not intended as therapeutic may raise a further number of unanticipated consequences (Allmark et al. 2009). Interviews require skill on the part of the researcher, including listening skills and question framing, as well as sensitivity (Marshall 2006) and reflexivity (Clarke 2005).

The interviews with all but two of the fifteen patient participants took place in the hospice day unit. This provided a perception of safety for the nursing staff (concerned around patient distress) and for myself. However, the interviews tended to be 'fitted in' around various activities and therapies, and consequently there were a number of interruptions. Most interviews lasted around one hour, with opportunities to reconvene if required. Interview schedules (see Appendices 13a, staff 13b, patient participants and 13c carers) designed to capture some of the issues identified within the literature review focused on issues around perceptions of hospice care, understandings around choice, the experience of accessing services and some reflections on future care. The interview schedules provided a flexible tool, rather than a scripted template, and used in conjunction with Pictor helped to enable participants to shape their own reflections. This approach is also in line with SCGT and approaches to theoretical sampling, which allow exploration of codes and categories within fieldwork. For example, staff and patients explored definitions of palliative care in response to probing based on a memo that identified different

understandings of palliative care. Following a detailed period of analysis, four further patient participants were recruited in order to explore categories and codes in more detail. Transcription of interviews was undertaken by either myself or with assistance (given my time constraints as a part-time student), and all interviews were reflected upon as field notes.

Some patient participants obviously struggled with fatigue during the interviews. I would also ask if they wished to stop, (either withdraw from the study or take a break) particularly as some of the discussion was obviously emotional. Despite such vulnerability, all wished to continue and appeared to wish to talk. The use of Pictor, in which individuals could plot Post-it® notes or would allow me to note a key word and plot on a blank piece of paper, was invaluable in coping with interruptions and fatigue. At the close of the interview, patient participants spent some time exploring the post-it®, rearranging or adding to further reflections.

I asked carers if they wished me to interview them at their home or at the hospice. All but two of the interviews with carers took place within the hospice. An interview schedule was utilised flexibly. It is notable that carers presented with the most distress when relating their experiences. Nevertheless, none wished to withdraw and none felt the need to take a support contact list. Despite attempts to encourage the use of Pictor, for this group the technique did not particularly 'work', possibly reflecting the emotional responses to the interviews and the need to simply tell their experiences, rather than stop and write.

Staff interviews took the form of either one-to-one interview or focus groups. The nurses working in the day centre, and in the community team, opted for a focus group interview, possibly reflecting the team dynamics within their role. The use of Pictor was not particularly successful in this group, possibly reflecting my positioning in the interview (section 4.5.2 provides an exploration regarding the use of Pictor as part of a discussion around interviewing 'elites'). The interview schedule covered similar topics as in the patient and carer interviews, although later interviews were able to compare key concepts

explored within the concurrent data analysis as part of an iterative process and allowing a means of triangulation of perspective.

#### **4.5.1 Focus Groups**

I conducted two focus groups, the first with three nurses within the day unit, and the second with seven community nurse specialists within the hospice team. The interviews utilised a series of prompts based on the semi structured interviews utilised in one-to-one interviews but were also guided by the participant experiences themselves and allowed some exploration of categories such as certainty and uncertainty, particularly with regard to Do Not Attempt Cardiac Pulmonary Resuscitation (DNACPR) orders. This approach fits with Flick's (2014, p. 250) validation of Morgan's (1998) assertion that focus groups may be useful in discussing interpretations of results, thus contributing to theoretical exploration of data within SCGT.

For the smaller group I was both facilitator and interviewer, but for the larger group, a colleague from the community nursing team, familiar with research methods having just completed her Master's degree, agreed to take notes whilst I facilitated discussion. Rather than use Pictor she was able to reflect key words on to a flip chart, which provided an opportunity to review key themes at the close of the focus group.

The smaller focus group refused to be recorded; possibly reflecting considerations of anonymity and confidentiality within a small organisation which Flick (2014) asserts can lead to reserved accounts. Indeed, the nurses suggested that they valued the opportunity to discuss but were uncertain how their views would be represented within the organisation, particularly criticisms of current practice around how choice was supported. Both focus groups lasted for no more than one hour (due to clinical time constraints) and detailed reflections recorded.

Charmaz (2006, p.27) argues that the interview is a negotiated interaction, in that “research participants appraise the interviewer, assess the situation, and act on their present assessments and prior knowledge, often in taken-for-granted ways”. Reflections of each interview, including setting, any odd issues, and thoughts on the meanings, were recorded after each interview as a means of reflexivity

#### **4.5.2 Using Pictor in practice**

Post-it® notes were utilised as part of a visual Pictor style approach to supporting one-to-one interviews (see section 4.3.2). King et al. (2013) advocate this as a useful tool for participants to plot and co construct data and reproduces graphically neat charts in presenting a study exploring collaborative working. King et al. (2013) recommend providing draft examples of charts to help participants ‘see’ how the process might look, and report that the technique is invaluable in guiding interviews, managing interruptions, as well as enabling participants to reflect on personal experiences. In this study, charting the post-it® notes was useful for similar reasons and in some ways acted as a ‘digging tool’ (Denzin 1989) cited in Williams & Keady (2012). As the researcher, I would ask if I could write down a key word to capture the essence of what they were saying, and place on a chart. At the close of the study, participants spent some time reorganising the notes, and reflecting as they revised the chart. This visual reorganising tended to cluster post-it® notes around admission, the experience of the hospice and the future, and provided an element of co construction within the interview. This usually led to a ‘there you have got it’ as though finally their story was told.

Despite provision of an example chart as advised by King et al. (2013) engagement with the Pictor approach was variable. Unlike King’s experience, in this study the charts produced were messy, and few participants wrote the Post-it® notes themselves. Van Drempt et al. (2011) and Elford et al. (2005) identify that participant involvement with writing can be challenging, particularly for participants with less dexterity and can cause some anxiety in revealing a deteriorating skill. In this study, patient participants did express concern at

writing, not necessarily through age, but often referred to having a 'chemo brain' and exhaustion. The visual Pictor approach was, however, useful in supporting engaged reflection and focus; and there was positive engagement with reviewing the charts. The first participant (P01) struggled with her medication, and fatigue, and was reluctant, suggesting it was a patronizing task. However, there were a number of interruptions and the chart proved invaluable in helping her focus on her story. At the close of the interview, she was fully engaged in making sense of the chart. (See Figure 6). One patient participant (see Figure 7) found the process less intuitive, and only provided one post-it although itself provided a stark visual indicator of what the hospice entailed (*'I'm going to die'*). Later charts tended to centre on a narrative from pre hospice admission to the future (see Figure 8)



Figure 6: P01 and Pictor



Figure 7: Patient 14 and Pictor



Figure 8: P13 and Pictor

Staff charts also reveal variable engagement with Pictor (see Figure 9 and Figure 10). Not until I was interviewing staff, did I realise that I was less assertive in asking staff to use a chart and Post-it® notes. Staff did not seem to understand what was required (for example Figure 10 indicates writing all points on one single note, rather than mapping) or resisted and I did not coerce. Possibly, the approach was not a 'good fit' for these interviews, which were more around practice, or guidelines, and did not easily lead to a temporal narrative. Edwards & Mauthner (2002) are mindful of the dynamic of power within qualitative research and Charmaz (2006) suggests that professionals often recite organisational rhetoric rather than personal views and this may account for staff ambivalence toward writing down their thoughts, particularly if there is unease as to how their words will be utilised and in what form. Indeed, a junior member of staff was reluctant to be recorded, or use a Pictor chart, cautious that managerial staff could access the material.

I was also less assertive with staff; for example, I felt fortunate to have an interview at all with one medic, and was conscious that I was a nurse, and he a medical professional. However, at the end of the interview he showed great interest and expressed that he would have liked to use Pictor as he was undertaking a course involving reflection and was interested in the process. My reflections on this incident capture an awareness of the issues involved in

interviewing perceived 'elites' and my own positioning within the power dynamics of the interview (see section 4.2.1 on reflexivity).



Figure 9: Staff CS05 and Pictor

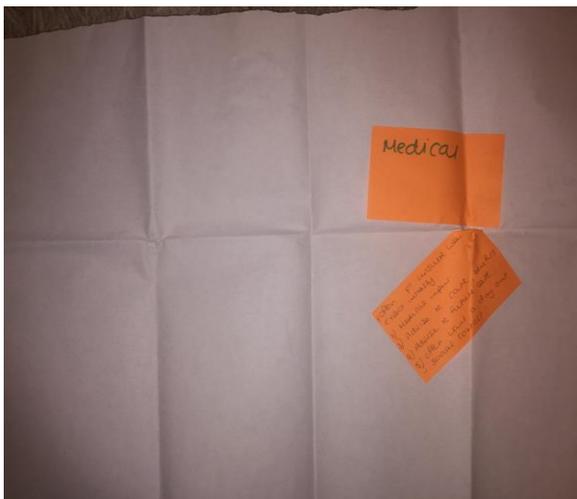


Figure 10: Staff CS02 Pictor.

Interviews with carers were often tearful and highly emotional, and stories flowed so quickly that stopping to write would have inhibited narration. Charts were variable and less coherent than produced by patient participants, and I tended to write the notes. Figure 11 is the chart of an individual who knew the history of hospice care but seemed to decline to map out her own thoughts. In many ways, the charts reflect the sense of disorientation within carer interviews, and this may have inhibited ability or willingness to map out their reflections.

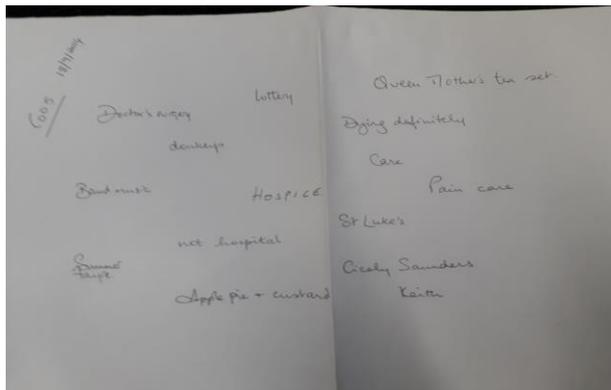


Figure 11:C05 and Pictor

### 4.5.3 Transcription

Digitally recorded interviews were transcribed by myself or with the assistance of an experienced administrator, and all anonymised. This presents as an unproblematic task but the emphasis on analysis commencing at the same time as data collection required that tapes were transcribed as soon as possible and memos and reflections diligently filed.

Transcription does not provide a precise copy of the interactive process of an interview - words are misheard, emphasis can be lost, and as Bazeley (2013) notes, transcription requires a return to the original text, as an odd omission of something misheard has the potential to change meanings. Indeed, Kvale (2009) is clear that transcribing is in a way a translation, and therefore a first stage of interpretation. Conversation analysis demands a detailed and complex system of coding to a degree not required for this study. Nevertheless, I did note spaces of silence, emotion and emphasis, whilst reflections of the interview would provide context or describe my thoughts on the interview itself.

The research administrator who undertook some of the transcription was familiar with issues of confidentiality and accuracy, and often provided insightful comment on some of the interviews. For example, whilst I 'heard' the desperation of C01 with whom I empathised a great deal as reminding me of my own father, she 'heard' a manipulative interaction. In his second interview, I was more alert as to how he managed the interview, and noted that he talked

for about 10 minutes about his thoughts, before realising that he had started before I had set the recorder. He then began again, almost recounting verbatim, suggesting that this was a well-rehearsed account and perhaps not likely to address particularly my questions but possibly serving his own agenda. The research administrator was also able to comment on interactions, for example, the tiredness of a voice, or where she felt the interview was particularly open and rapport working well (Appendix 15 provides an extract from an anonymised patient participant transcript). All transcriptions, whether prepared by myself or not were listened to repeatedly following transcription, with additional comments to emphasise silence, emphasis and emotion.

## 4.6 Data analysis: coding

Each data set (Patient, Carer, Staff) was coded in a separate NVivo database and analysed separately but diagramming and mapping allowed a triangulation of perspective. Memos and diagramming helped to build the overarching core category of transience and transition, and so informed a grounded theory around the uncertain, fragile and transient nature of transition to hospice care.

The first stage of line-by-line open coding was a manual process undertaken in each transcript (see Figure 12). Open coding allows identification of patterns or clusters of recurring topics.

Open Coding	Text
Blockage  Asking permission to ask  Turning out bad  Being warned	<p style="text-align: center;">But as it was decided not to go and I'm glad because I would have been back in time before the bowel blockage happened but only just. It's one of the things that I said could I ask what could happen and they said you could have a bowel blockage and that would be bad in [E] but it would be very bad in [A] so that was it and as it turned out I thought you know when I did have it I thought he warned me about it was it this that I'd been saying about. But they</p>

Finding cancer	<p>didn't know that it was cancer so until I had that blockage but erm but anyway I spoke to when I saw [SA] he erm, really nice man, and he was saying get you some comfort for a start, things have changed, obviously aware of what happened to my husband as well but tried not to from the start but it is hard ... you put a face on but er and he said because I said to him how do I get referred to [SL] as I say it was from the start so this would be the beginning of December 2011, I should have been flying on the 17<sup>th</sup> December, that's how close it was to going to my daughters and he said a GP can refer you so he was letting the GP know and I was GP know 'cos Macmillan nurse 'cos there was no Macmillan nurse so I had nobody giving me advice there so it's through already knowing about it that I asked and I had somebody</p>
Offering comfort	
Knowing what happens	
Caring past	
Putting on a face	
Asking for referral	
Seeking help	
Looking for advice	
Worrying about daughter	
Letting GP refer	
No macmillan nurse	
Not having anyone	
No advice	
Past experience	
Getting somebody	

Figure 12: Sample of open coding

The transcriptions were downloaded into QSR-NVivo, with the open codes created as nodes. Bazeley (2013) details how Nvivo provides a number of facilities to help explore patterns within the data including use of mapping and matrix facility, ability to install hyperlinks, and coding of visual materials, as a means of exploring linkages between codes and stored memos. Charmaz (2013, p.299) cautions that relying on software to code can lead to a technical and descriptive account of the data. Despite the many facilities offered by this software using a 'cut and paste' process rather than all the features that Nvivo offers, allowed me to focus on the interviews and data rather than the software. Codes were reorganized in 'hierarchical trees' and explored for variance and similarities. See Figure 13 for an example of a developing NVivo patient coding frame.

Unlike Hutchison et al (2010) who managed memos using NVivo, I used Microsoft Word to store and file, reflecting an intuitive and reflective practice that often occurred spontaneously and at odd moments. I recorded memos in a notebook that was readily to hand and then entered into a word filing system.

Name	Sources	Referenc...	Created On	Created By	Modified On	Modified By
financial worries	2	2	30 Sep 2015 12:07	FMW	5 Oct 2015 13:11	FMW
Feeling alone	3	10	21 Sep 2015 15:26	FMW	12 Oct 2015 21:23	FMW
Feeling secure	2	2	21 Sep 2015 15:27	FMW	12 Oct 2015 21:13	FMW
Getting terminal status	3	4	20 Sep 2015 18:28	FMW	11 Oct 2015 14:52	FMW
being assessed	1	1	30 Sep 2015 11:42	FMW	30 Sep 2015 11:43	FMW
Being with people wh...	3	4	20 Sep 2015 18:37	FMW	12 Oct 2015 21:15	FMW
chemo brain	2	3	5 Oct 2015 13:16	FMW	11 Oct 2015 14:05	FMW
choosing or losing act...	4	13	30 Sep 2015 11:31	FMW	12 Oct 2015 21:03	FMW
dnacpr	3	3	5 Oct 2015 13:31	FMW	12 Oct 2015 21:20	FMW
first day	1	1	5 Oct 2015 12:57	FMW	5 Oct 2015 12:58	FMW
full time patient	3	7	5 Oct 2015 12:53	FMW	12 Oct 2015 20:56	FMW
Shift in prognosis	4	22	30 Sep 2015 11:35	FMW	12 Oct 2015 21:25	FMW
shock	2	2	11 Oct 2015 14:52	FMW	12 Oct 2015 20:57	FMW
telling others	3	6	5 Oct 2015 13:26	FMW	12 Oct 2015 21:23	FMW
treatment too much.	3	11	5 Oct 2015 13:16	FMW	12 Oct 2015 21:04	FMW
insecure sanctuary	2	3	20 Sep 2015 18:27	FMW	11 Oct 2015 14:44	FMW
psycsocial support	3	7	20 Sep 2015 18:38	FMW	12 Oct 2015 21:21	FMW
time limited	4	10	30 Sep 2015 11:55	FMW	12 Oct 2015 21:21	FMW
Knowing SI	4	9	21 Sep 2015 15:26	FMW	12 Oct 2015 21:16	FMW
life affirming	3	11	30 Sep 2015 11:18	FMW	12 Oct 2015 21:17	FMW
Managing the certainties	2	2	20 Sep 2015 18:29	FMW	5 Oct 2015 13:14	FMW

Figure 13: NVivo Patient Coding Frame

Focused coding enables the relationships between patterns and processes in the data and leads to the formation of categories. This process moves analysis away from description, cited as a concern for researchers in the 'doing' of by both Glazer and Charmaz in the doing of grounded theory (Charmaz 2012). Categories were further refined to build into core categories, using a process of mapping and exploring how categories relate to one another, particularly looking for variance. I did attempt to use elements of situational analysis in terms of mapping and diagramming, and exploring what would happen if a particular category did *not* happen as a means of exploring process. This was particularly useful in capturing the action and dimensions of a particular category and reflects in some ways the term 'social inversion', described by Clarke and Friese (2007, p.391) in the work of Star (1999) as a means of

exploring the more invisible aspects of a social world. This approach was specifically useful in exploring what was 'actioned' by the use of the journey metaphor prevalent in staff interviews.

#### **4.6.1 Data analysis: Mapping**

Diagramming and memoing helped to explore the anomalies and meanings within the data in more depth. Ideas were mapped using diagrams, to look for relationships. The use of mapping and diagramming as a means of exploring data is identified by various proponents of grounded theory including, Lempert (2007), Charmaz (2006), and Williams & Keady (2012).

Athelston & Deller (2013) suggest that 'humans are inherently visual' and suggest that visual methodologies are increasing particularly as they offer to create a sense of meaning and focus on what is important for participants. My previous research experience within a project using experienced based design (see Wilson, et al. 2011 and Bate & Robert 2007) utilised a co constructionist approach with regard to service user and service design using visual mapping and modelling approaches with services to co construct understandings around service delivery. Mapping or diagramming also presents as a means of making sense of data (Flick 2014), and Clarke (2005), in a further evolution of grounded theory described as situational analysis, uses a process of mapping to enable a discursive analysis of the 'situation' in order to help position and situate the discourse within a particular context. Mapping was a useful process in helping to explore the data and Figure 14 provides an example of an early 'map' exploring how patients came to use hospice services.

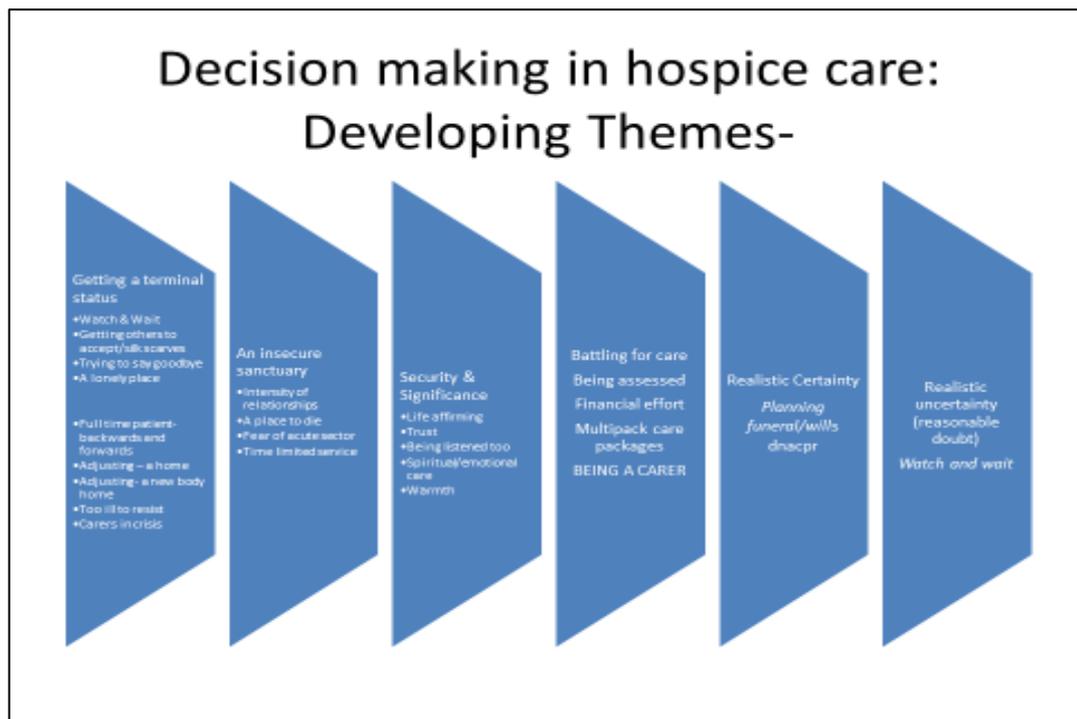


Figure 14: Mapping and coding

### 4.6.2 Data Analysis: Memoing

Birks et al. (2008) describe memos as key to data analysis, providing a contemporaneous record of thought processes, helping to provide a reflexivity and transparency around analytical decisions. Hutchison et al. (2010) provide an overview of ten different types of memos in SCGT, including a research diary, reflective memos, conceptual memos, and memos linked to the literature. In their study, Hutchison et al (2010) systematically record and store memos within NVivo, attaching them to nodes, categories, and linking to interview reflections and analytic memos. In my practice however, I utilised a word filing system, along with a study journal and interview reflections and explored connections between categories and codes using diagrams. This seemed to retain my focus on the data rather than that analytic process or technicalities of a database. I also returned to the original transcripts and recordings to ensure that the coding process retained what I felt to be the main essence of the interview. The research diary captured issues around data collection, any literature that appeared relevant, e-mails, as well as personal reflections around concerns such as ethical difficulties or whether I had articulated a set of codes in a way that captures the meanings and sense of the data.

Analytical memos focused on categories, particularly aimed at exploring more deeply the meanings of key phrases or codes, and allowed me to unpack the processes behind particular patterns in the data, or as Timmermans & Tavory (2012) describe, 'puzzling out'. Such a problem solving process is both inductive and abductive (the latter described as a creative process looking at the data for what is surprising, unusual or not fitting with existing ideas). Appendix 17 provides an example of a memo exploring an analytical category around an 'insecure sanctuary', which explored how the refuge of the hospice was actually double edged and insecure. My initial analysis of how patient participants resisted the hospice but then appeared to find a place of sanctuary or refuge appeared to offer a confirmation of Nolan et al.'s (2004) work around the senses framework in relationship centred care, which cites security as a valued entity in care. However, in revisiting the patient interviews I was able to contrast the data against the senses framework and became sensitive to issues of insecurity within the initial theme of the hospice as refuge or sanctuary. This insight facilitated development of the code to 'insecure sanctuary' and contributed to the development of overarching core category of transience within transition.

The staff accounts also used a metaphor of the 'patient journey' and this at first presented as a means of understanding how patients moved linearly from community, to day hospice, to inpatient to deceased. However, patient and carers did not use this metaphor so explicitly, nor were these necessarily the destination points for all patient and carers. Further testing of categories and analytical memoing enabled a consideration of what purpose the journey metaphor might serve. Initially I had thought that the journey might be an overarching theme, however, further memoing and coding enabled a deeper conceptualisation of the journey as means of coping with and conceptualising the uncertainty of transition and transition at end of life.

#### **4.6.3 Data analysis: Theoretical saturation**

Charmaz (2006) and Flick (2014) state that theoretical saturation is complete, not when interviewees present repeatedly similar stories or when no new codes

are found within the interviews, but when the dimensions of key core categories have been sufficiently explored for variance, temporality and process in order to support theory development. Saturation of core categories occurred when the core categories had been examined and re-examined for variance and similarity of patterns. There is some critique of theoretical saturation, with some (for example Flick 2014, p.417) suggesting that it is likely that reinterpretation and multiple readings of data can render saturation as unachievable. Indeed, Timmerans & Tavory (2012) argue that analysis requires a process of 'defamiliarisation' and that it is possible to look at data in different ways, at different times. In this study, where there was sufficient data to support in depth exploration of core categories, then data collection ceased. My decision to stop collecting more data was also in part pragmatic and part method, as persisting indefinitely was proving impractical in the field (and in trying to repeatedly access carers or staff I was worried I was beginning to outstay my welcome).

#### **4.6.4 Validation and member checking**

Doucet & Mauthner (2002) argue for a stance of 'knowing responsibly' and researcher accountability. This study aimed to co-construct rather than use feedback in the form of respondent validation in order to validate analysis. Respondent validation is problematic in that analysis may not reflect the viewpoint of participants, and yet this in itself does not reduce the credibility of the analysis (Bryman 2016, p. 385). Constructivist approaches argue that member validation assumes the notion of a single 'truth' or 'reality' rather than an interpretation (Silverman 2013). Similarly Flick (2014) cautions that although triangulation can provide a form of validation, this is no more valid than any other perspective. There is an argument however, that triangulation can offer broader perspective (Heale & Forbes 2013), and if conducted as part of analysis, can accompany the comparative and iterative nature of grounded theory (Shih 1998). In this study, the use of triangulation enabled the exploration of multiple viewpoints and theoretical sampling enabled further exploration of categories.

However, in line with a co-constructivist approach, there was no complete disregard of member validation within this study. Pictor, as well as offering the potential of a 'digging tool' (Denzin (1989) cited in Williams & Keady (2012), offered a form of co-construction, and arguably a source of member checking *within* interviews. In 2015, I was invited to present the progress of the study and any initial findings to the management team (see Appendix 18). This provided a means of exploring early analysis and 'maintaining contact with the field' (Silverman 2013, p.288). My observations at that point resonated with concerns within the hospice team, particularly around public understandings of hospice and issues of inequality of access for BAME groups. The complete study has not yet been presented and the question remains however, of whether respondent validation offers validity or a further viewpoint.

#### **4.7 Researcher reflexivity**

Some of my responses and reflexivity regarding the actual 'doing' of the research focus on micro ethical considerations. Kvale (2007) argues that micro ethics requires judgement and a 'thinking on feet'. I would hope that I was able to reflect more deeply in a considered response to issues arising in the field, rather than respond reactively, particularly as reflexivity is a key aspect of SCGT.

Reflexivity and researcher positionality have been emphasised as key characteristics of SCGT. Charmaz (2007, p.15) is clear that researchers and research participants make assumptions around what constitutes reality, and their 'respective views and actions influence each other'. McGhee et al. (2007) also refer to the work of Reed & Proctor (1995) which argues that researcher positioning as either an insider or outsider or as a hybrid, shapes researcher perceptions of data. My positioning in this study partly echoes the work of Eschenbruch (2007) in a German hospice, in which the positioning of the researcher from outsider to insider - from academic to care worker - and then to outsider/insider as a researcher shapes the research context, influencing interactions and perceptions. I was a researcher, a palliative care nurse and a family carer and would therefore describe myself as a 'hybrid insider', however, my positioning oscillated from insider (nurse) to outsider (researcher). In some

ways, an outsider/insider split is an overly simple dualism particularly within a large organisation. For example, being an inpatient nurse facilitated support from some staff, but less from others, particularly the specialist palliative care community specialist nurses, or by those professionals who were not nurses and to whom I was unknown (an outsider). Later in the study, a further positioning occurred in a shift from researcher to carer.

As insider, I had assumed that having worked in palliative care I would be somewhat inured to death and dying to a degree that perhaps a novice researcher in this field would not be. The hospice is a supportive environment and I did have the ear of a bereavement counsellor should I require this. I had promised to send a review of the study to participants but as time moved on, I was aware and uncomfortable that I had not done this. It was only after reflecting on Burle's (2017) work around how researchers may subconsciously react to researching death and dying, that I realised I had not consciously sought to find out what had happened to patient participants nor their carers, possibly realising that most are now deceased, and as a form of defence. I also did not anticipate that some of the work could be distressing for others. For example, the research administrator provided an invaluable opportunity for me to debrief, and would discuss some of the interviews she helped to transcribe. However, the study began to raise a number of very personal issues for her. Taylor & Bradbury-Jones (2011) identify that ethics committees often deliberate over ethical concerns in order to protect the researched, but often overlook the needs of those supporting sensitive research. Such observations will I hope inform my future research.

Interviews mostly took place at the day unit (place of interview was mutually negotiated) and I believed this was less intrusive than interviewing at their home. The hospice team and I also felt reassured that nurses were on hand should participants become distressed and require support. On reflection, the hospice also provided me with a buffer against the more emotional home based interviews. Indeed, those stories that are most vivid and in some ways the most painful, were those which took place in people's homes, or whose stories were particularly close to my own experiences. Only two carers and one patient

requested I interview for their convenience at their own homes and these interviews reflect the work of Sivell et al. (2015), who suggest that the home environment leads to a 'patient-led dialogue' which can facilitate rapport but can also shift the dynamics of the interview. Power in research is supposedly in the hands of the researcher; however, power can be more subtle. Interviews in homes were the longest interviews, and the context was intensely personal with photographs, ornaments and letters. One carer had set out her front room as a shrine for her deceased son and her deceased husband. Another patient participant had received treatment at the oncology unit the day before and was taking high doses of steroids. The interview in her home took three to four hours, including numerous interruptions, and I was emotionally drained but happy to support her. She was alone and anxious and I realised that she knew she struggled the day following treatment. She later explained that the interview was useful, as she knew she would have somebody with her to talk to and to show me some of her possessions and their legacy that were so important to her.

Maton (2003) suggests that reflexivity can be a form of narcissism; however, in this instance it was important to explore my readings of the data with caution to ensure that analysis was not simply the transference of my own emotions. In analysing the transcripts, I was mindful to return to the interviews and memos in order to ensure that my emotions were not shaping my response to the data but grounded in the voices of those I had interviewed. When my own father became unwell and died, the study became very difficult to attend to without attributing my own emotions and particular my frustrations and anger on to the analysis. There were some interesting moments when the research also served to colour my experience as a carer, particularly when I was asked to complete a third priorities of care document, and asking the staff to consider why they were so keen to record his wishes, given his wishes could not be met. This event engendered a more conscious attention to reflexivity, particularly when exploring the carer data. I was careful to return to the question of whether it was my autobiography or my emotions I was exploring, rather than theirs. Such experiences formed a dual function in helping to check that my interpretation was not overly coloured by my own experience but also provided a reasonable

basis to assume that the findings did resonate with the experience of being a carer. In the writing up, I was however, mindful to return to the original data and memos to ensure that my own emotions were not shaping my response to the data and that the analysis remained grounded in the voices of study participants.

#### **4.7.1 Leaving the field**

The study information sheet did offer a report or summary of findings to all participants, although it was never the intention to return scripts to participants. A summary report will be presented to the hospice management team. Many staff have since left the hospice however, and the management team may best advise how to provide feedback. With regard to patient and carer participants, Burles (2017) reflects on how she avoided following up participants who would likely have died. On reflection, I recognise that I have also subconsciously not traced patient and carer participants, recognising that many will have since died. I would be reluctant to post transcripts or a report to individuals and potentially cause distress. This is an ethical consideration, which may be erroneous and perhaps shaped by my own assumptions around how far participants would be willing or able to revisit the themes of the study.

### **4.8 Summary**

The above outlines the background to social constructionist epistemology and SCGT method but also provides a detailed account of how the study was conducted; shaped in part by ethical issues at both a micro and macro level, as well as the pragmatic considerations of real world research. The concluding chapter discusses the limitations and strengths of the study, however the detail provided here aspires to a transparency of process and analysis, and attempts to address the study question with rigour. This study has explored the experiences of participants, grounding the data within the data, and leading to an overarching theory of 'transience and transition'. The following chapter will present the findings.

# Chapter 5: Findings

## 5.1 Introduction

The following three chapters present the findings from staff, patient and carer interviews. There are number of ways to present the large amount of data amassed within a qualitative study. Chapter four (Methods and Methodology) provides an epistemological overview and background to the study design and emphasises reflexivity as a key element throughout the development of a constructivist study. The concluding chapter will provide an overview of the study strengths and limitations in relation to the criteria below. Charmaz (2006) is clear that a number of criteria around credibility, originality, resonance and usefulness must support theory generation. Charmaz (2000, p. 522) states that in order to do justice to patient experiences, it is important to render and compose the story, rather than describe. The data is therefore organised into three distinct datasets that provide a triangulation of the three perspectives around the study aims, which are as follows:

- To explore how service users (patient and carers) facing end-of-life come to use hospice services;
- To examine how individuals make sense of choice within the context of palliative care;
- To explore the impact of ethnicity, age and gender on choice around hospice care;
- To explore how patient, carers and health care staff negotiate care decisions;
- Finally, to consider the role of end-of-life care planning tools in facilitating future care decisions.

Selection of data requires a judicious process of ensuring that the data represents the voices of all participants from each data set, and captures the essence of each category. The central overarching theme linking the three datasets is that of 'transition & transience'.

By contrasting the perspectives of health care staff, patients and carers around the core categories of transition (being referred, becoming terminal, and responding to uncertainty), it is possible to identify areas of similarity and dissonance between the three perspectives. Accessing hospice services denoted a transitional shift from curative to non-curative prognosis. Staff, patient and carer accounts reflected that prognosis was unpredictable and therefore transition was less a step from one phase to another, but was instead a shifting and transient concept. Table 9 provides a review of themes across the three perspectives. Each data set conceptualises the overarching theme **‘transition & transience’** under the three core categories of **‘being referred’**, **‘becoming terminal’**, and **‘responding to uncertainty’**.

Table 9: Mapping key themes and sub-themes across three datasets

Transition & Transience ¶			
Transition ¶	Staff perspectives ¶	Patient perspectives ¶	Carer Perspectives ¶
Being referred ¶	Going to the hospice ¶	Going to the hospice ¶	Going to the hospice ¶
	Looking for openings ¶	Giving it a go ¶	Reaching the end of the line ¶
	Getting people through the door ¶	Shouting for help ¶	Wondering how long ¶
	Referring BAME patients ¶	Stepping into a place of death ¶	¶
	Referring older people ¶	¶	¶
¶	¶	¶	¶
Becoming terminal ¶	Supporting the patient journey ¶	Becoming terminal ¶	Coordinating care ¶
	Being there ¶	Finding an insecure sanctuary ¶	Being vigilant ¶
	Managing carers ¶	Managing the everyday ¶	Taking time out ¶
	Mediating & safeguarding ¶	Supporting others ¶	¶
	Recognising carer needs ¶	¶	¶
¶	¶	¶	¶
Responding to uncertainty ¶	Managing Uncertainty ¶	Coping with uncertainty ¶	Coping with uncertainty ¶
	Documenting choice ¶	Coping with uncertainty ¶	Trying to have conversations ¶
	Trusting intuition ¶	Managing the certainties of death ¶	¶
	Understandings of hospice and palliative care ¶	Understandings of hospice & palliative care ¶	Understandings of hospice & palliative care ¶

The first dataset presents the data from the staff interviews. Figure 15 presents the conceptual framework of **'transition & transience'** in relation to the staff data.

## **5.2 Staff perspectives of Transition & Transience**

The remainder of this chapter will present the findings from the staff interviews. The term 'staff' captures the range of health professionals interviewed and also includes 'non-professionals' who provide a range of supportive services (for example, the manager of the volunteer driver service). Ten one-to-one semi structured interviews were conducted with a range of staff from both a referring oncology unit and hospice staff, and two focus groups (n=3, and n=7) were conducted with nursing staff based within the hospice. Table 10 provides a profile of staff participants (see Chapter four for details of sampling and recruitment).

Staff describe their role as supporting a transitional process from admission to hospice care. However, rather than a linear journey from hospital to hospice and death, transition is recognised as uncertain and transient, with the consequence that interventions and management of 'the journey' are often intuitive and implicit. Figure 15 provides an overview of the overarching theme **'transition & transience'**, and illustrates the key themes and subthemes within each of the core categories: **'being referred'**, **'becoming terminal'** and **'responding to uncertainty'**.

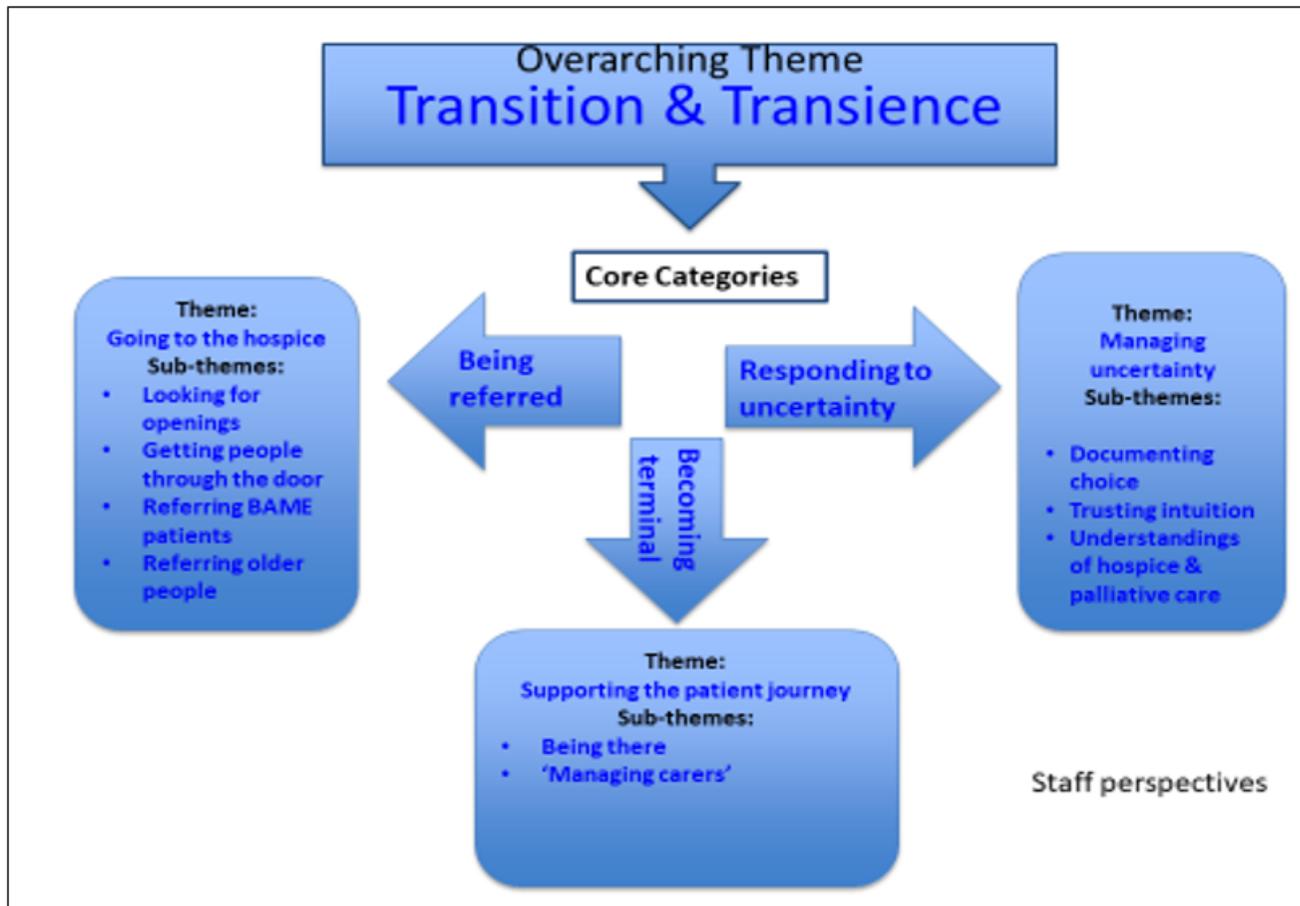


Figure 15: Staff perspectives on Transition & Transience: a thematic framework

Table 10: Profile of staff participants

ID	Role	Place of work	Qualification	Referring Role	Description of interview
CS01	Nurse	Therapies & Rehabilitation Unit (TRU)	RGN	No	One-to-one interview Not recorded- field notes only
CS02	Nurse	Therapies & Rehabilitation Unit (TRU)	Palliative care specialist degree	No	One-to-one interview
CS03 Focus Group	Nurse focus group	Therapies & Rehabilitation Unit (TRU)	RGNs including one with palliative care specialist degree	No	Focus Group of 3 staff nurses Not recorded- field notes only
CS04	Allied Health Professional	Hospice	Ordained	No	One-to-one interview
CS05	Support staff	Hospice	Unknown	No	One-to-one interview
CS06 Focus Group	Community Nurse Focus Group	Hospice Community Services	Specialist palliative care qualifications from diploma, modules to degree and masters	Yes	Focus group of 7 Specialist hospice community nurses
CS07	Medic	Hospice and Oncology Unit	Specialist in palliative care	Yes	One-to-one interview
CS08	Nurse	Oncology Unit	Specialist palliative care qualifications, oncology and community nursing	Yes	One-to-one interview
CS09	Nurse	Oncology Unit	Specialist palliative care qualifications	Yes	One-to-one interview
CS10	Manager	Hospice	Specialist palliative care qualifications	No	One-to-one interview
CS11	Nurse	Oncology Unit	Oncology qualifications	Yes	One-to-one interview
CS12	Manager	Hospice	RGN, and management qualification	No	One-to-one interview

## 5.3 Staff perspectives on ‘being referred’

The core category ‘being referred’ specifically addresses the study aim of exploring how people come to use hospice services. There was a sense in staff interviews that referral was a tentative process, possibly reflecting acknowledgement that referral was an emotional transition for patients and families from curative to palliative care. Staff appear to use a number of strategies in facilitating referral explored in the subthemes of ‘looking for openings’, and ‘getting people through the door’. Staff also discuss the referral of patients from Black and Minority Ethnic (BAME) groups and the issues involved in ‘referring older people’. Table 11 presents the sub-themes of ‘being referred’.

Table 11: Staff perspectives on referral: themes and sub-themes.

Key Theme	Sub themes
Being Referred	Looking for openings
	Getting people through the door
	Referring BAME patients
	Referring older people

### 5.3.1. Looking for openings

The subtheme ‘looking for openings’ describes the highly tentative process of offering hospice care to patients and families. Staff with a remit of referral from the local oncology unit and hospice community nurses were aware that patient recognised the ‘hospice’ negatively as an implicit signifier of a non-curative condition and ultimately death:

*I think even before referral sometimes; you can hear the silence when we introduce ourselves. Hospice Community Nurse Focus Group (CS06)*

*I also hear people and patients say that coming to this building it's an overwhelming moment of clarity about what's going to happen to them.*

Manager (CS10)

Introducing the hospice as a possible place of care was a potentially highly sensitive interaction. Knowing when it may be appropriate to broach the possibility of hospice care appeared to be intuitive using verbal and nonverbal cues (rather than a set of criteria). The process of gauging patient readiness was therefore tentative as the following description of looking for a 'green light' indicates:

*We discuss those things with patients who are ready to discuss those things, it's just sometimes waiting for the green light because we tend to be asked those questions with patients not ready, then pull back and then we'll have that discussion again further on in their journey*

Community Nurse Focus Group (CS06)

There was a sense however, that signals may be difficult to discern, and if cues misread, then patient trust could be lost and referral postponed. The following extract captures the tentative process of probing and testing:

*Interviewer: So what sorts of cues are you picking up from someone, what are you looking for in your conversations?*

*CS09: I suppose it would be everything with their body language, how they're talking to you, what they're evading, what they are wanting to talk to you about. Sometimes you may have to push them in a little bit of a direction and see how much they push you back. Some people you could go in with a great intention of talking about the hospice, you get there, you start to talk to them in the preamble before you sort of mention things and then half way through that conversation I might back off it and think it's not right this time to do that. Sometimes you can do it and it goes very badly wrong.*

Nurse (CS09)

### 5.3.2 Getting people through the door

'Getting people through the door' refers to the efforts involved in encouraging patients to accept referral. A number of strategies were deployed by staff to encourage patients to accept hospice care, including an emphasis on presenting the day unit as a short-term intervention, a focus on pain management, and as well as tactically enlisting the support of carers. For example, to overcome the fear of entering a 'place of death', the hospice day unit was emphasised as a short-term day service in an effort to dispel perceptions that patients would be admitted to die:

*Erm we usually say that erm it's symptom management erm and when we say that we always stress that it's very short term and that the hospice staff will be looking at where you go once your symptoms are managed so it's not a long term thing or it's end-of-life care which is maybe a week or two weeks possibly.*

Community Nurse Focus Group (CS06).

Providing the opportunity to view the service before acceptance offers a further strategy for 'getting people through the door' and patients were encouraged to visit the unit before accepting referral:

*So encourage them, get them through the door, meet staff, have a little look round see what we're doing and then they've got an informed, more informed choice if you like cos they've been in the building and they 've seen other people you know they can make a connection, can't they?*

Nurse (CS02).

Where there was stalling or indecision on the part of the patient, family carers were encouraged to visit and report back, almost as a form of reconnaissance:

*I've certainly had quite a few relatives that I know come and have a look and that just seems really helpful because you can see pictures and people can tell you but actually if your spouse was to say oh it looks really nice or the coffee machine was great you know actually to have some experience from somebody that they trust I think that can mean a lot.*

Medic (CS07).

Referring staff also present the hospice as a place to receive support for physical aspects of care, with pain management acting as a potential trigger for referral:

*I don't exaggerate it but if it's there [pain] I will mention it just as a sort of extra trigger point.*  
Nurse (CS11).

A focus on pain management appeared to offer a tangible and potentially satisfying outcome for staff and patients as captured in the quote below:

*You can support them through, walk alongside them, all those things we say but you can't change it whereas you know you've got a bit of a chance with a symptom, a physical thing, that you can improve.*  
Manager (CS10).

An emphasis on the more tangible aspects of care, such as pain management did not preclude support for the psychosocial aspects of care but was seen as helpful in creating a level of trust and enabling a gradual shift toward support for the more existential and psychosocial elements of care:

*Because they're wanting all their pain sorted out but for me it's about putting funeral arrangements in place, putting all of those things with children in place, putting memory boxes, how they help their families to understand what's happening to them so referrals from community come to me. I am usually more of a practical nature rather than faith or spirituality. They are a spirituality but they manifest themselves in practical things and once we get rid of some of the practical things and because they trust me then we deal with some of the psychological, spiritual and if there's a faith, faith based work that they want to do.*  
Allied Health Professional (CS04).

### 5.3.3 Referring BAME patients

One of the original study aims was to explore access to hospice services by Black and Minority Ethnic (BAME) groups. Chapter four provided a background to some of the issues around recruitment of participants and reflects that the study sample is indicative of the low numbers of patients from BAME groups accessing hospices generally. The interviews with staff did however explore issues of BAME access to services. A prime reason given for the lack of a BAME presence at the hospice was the belief that BAME groups, particularly the local Asian community, tend to care for their own. Staff assumed that family, not hospice care, was the preferred care option and cultural norm for BAME groups:

*I'm just thinking of a lovely lady who comes to clinic but her family do everything for her and will continue to do everything for her so I can predict that there's no way she'll end up in the hospice because her family will do all the caring for her. I suppose it's that, now I'm not speaking for everybody but certainly for this family she lives with her son and the family and it's very much they see it as their role to look after ageing mum.*

Medic (CS07).

Some staff however, acknowledged that assumptions around family based care within BAME groups were problematic, particularly with regard to intergenerational changes, and the changing role of women. The possibility that a Western vision of palliative care can preclude access was a moot point within the interviews, and indeed, there was some reflection as to who was meeting the needs of BAME patients facing end of life:

*Erm and we don't understand the choice and I think it's more complex than just people look after their own because you've got every generation get further away from their culture and adopt more of the culture that they live in so you've got some...or go the other way but we've got there are certainly in some of the patients that we've seen in the community there's a lot of tension around the woman's role with some of the Muslim families where the next generation daughters have got jobs and it's, you know there's a real sort of tension*

*between their duty and their family responsibilities and their own kind of you know life and things so it's much more complex than you know you can't just say it's one thing.*

Manager (CS10).

### **5.3.4 Referring older people**

One aim of the study intended to explore the impact of age on access to services. Staff working in the local oncology unit and the hospice community team revealed that older people presented a particular challenge with regard to identifying when and how older people should receive palliative care. Older patients identified as imminently dying, may be 'fast tracked' to access care in a hospice. However, prognostication was challenging, as illustrated below:

*I emailed the consultant and said you know do you think they meet the fast-track criteria and both consultants were very clear that they didn't, that they have a very stable disease you know that we shouldn't be looking at fast-track we should be looking at alternatives erm both of them died last week within 2 weeks of being told that you know it wasn't fast-tracked so it isn't an exact science.*

Nurse (CS08)

Nurse (CS08) suggested that older people identified as requiring long-term palliative support and who required supportive care in excess of four visits a day could be encouraged to enter care home provision rather than hospice care.

Interviewer: *In a nursing home?*

CS08: *Well it depends, they will either fund, again it's all to do with money so it costs about £500 per week for somebody to have four calls a day, if people are needing more than 4 calls a day then the health authorities won't provide that, they will say that person needs to be in a nursing home with 24-hour care which is the same cost.*

Nurse (CS08)

Currently in England, older people who require care home support are 'means tested' and if savings or resources are in excess of the statutory requirement, they become self-funding, using the proceeds from the sale of property or

savings to pay for care fees. The focus group with community nurses suggests that means testing can lead to conflict between services providers and carers:

*I: Yeah. Is the relative a bit of an obstacle sometimes?*

*P: Relatives? Oh god massive. No they are more of an obstacle I would say than the patients, certainly with the elderly, frail, going into nursing homes.*

Nurse (CS06)

Transfer to residential/nursing home care appeared to preclude access to hospice inpatient services, even where palliative care needs later increased. Staff participants identified that this can be confusing and distressing for carers, particularly if carers believed that the hospice, rather than a care home would provide a more appropriate place of care at end of life. Admission to a care home however, appeared to be recorded within formal care planning as discharge to 'home' and referral to a hospice at a later date regarded as unnecessary within the agenda of supporting end-of-life care 'at home':

*Or wanting hospital treatment and this is the preferred options of care where you're meant to be cared for at home and the minute you arrive in a nursing home that's meant to be your home well actually it's not 'cos you've only just arrived but you know the system think it is and hospital often say it's not appropriate for you to come back in so they're left with us but nobody explains the options and it can be quite painful for relatives and patients.*

Community Nurse Focus Group (CS06)

The interviews also reflected current debates around which conditions are the remit of hospice care, particularly with regard to frail, older people, those with dementia and other long-term conditions, and suggest an uneasy tension between balancing resources and access:

*I think we also get referrals to the inpatient centre that needs things like Fast Track completed, who needs to go to a nursing home and rather than that being done it's ... some of this is sort of perception that we have that it's sort of a golden ticket to everything which of course we don't*

Manager (CS10)

### **5.3.5 Summary of staff perspectives of ‘being referred’**

In sum, the core category ‘being referred’ captured how staff perceived and facilitated access to hospice services. The subthemes ‘getting people through the door’ and ‘looking for openings’ indicated that staff were mindful that hospice care presents as a signifier of a non-curative condition, and conversations around hospice referral were tentative. Getting people to accept referral was an intuitive process of gauging readiness whilst at the same time using a number of strategies to build trust, and particularly emphasising pain management.

Exploring how people from BAME groups come to use hospice services raised a number of questions for staff particularly around family care. There was a sense of unease and questioning around whether assumptions around family care were possibly erroneous and ethnocentric, particularly as intergenerational patterns of family caring may be shifting within BAME groups.

Referral of older people to hospice services presented a challenge given the uncertainty of prognosis and best place of care. Financial provision of services and means testing presented a source of tension between carers and older people and staff, and acceptance of a care home could preclude access to hospice services even should palliative needs increase. Such dynamics question notions of autonomy and choice for older people.

## **5.4 Staff perspectives on ‘becoming terminal’**

The core category of ‘becoming terminal’ provides insight into how staff negotiate care decisions in the transition to hospice care. Two key themes ‘supporting the patient journey’ and ‘managing carers’ and associated sub themes support the core category of ‘becoming terminal’ (see Table 12). Each

theme and associated sub-theme is explored below, and first is the theme 'supporting the patient journey'.

Table 12: Staff perspectives on the 'becoming terminal': themes and sub-themes.

<b>Key Themes</b>	<b>Subthemes</b>
<b>Supporting the patient journey</b>	<b>Different journeys</b>
	<b>Being there</b>
<b>Managing Carers</b>	<b>Mediating &amp; safeguarding between carers and patients</b>
	<b>Recognising carer needs</b>

### **5.4.1 Supporting the patient journey**

All staff participants used the phrase 'patient journey' to describe patient transitions to the hospice. Two subthemes capture the key elements of supporting the patient journey and these include recognition of 'different journeys', and a sense of 'being there'. The 'journey' was a commonly used term throughout the staff interviews but was conceptualised in different ways by different staff. For example, a support staff member (CS05) describes stepping on and off a cartwheel, whilst a medic (CS07) describes a 'step down' journey as the health deteriorates, and a specialist oncology nurse describes a taxi journey accompanied by a range of supporting staff. Journeys also appeared to differ according to patient diagnosis and prognosis reflecting a sense of uncertainty around the journey:

*I mean the head and neck nurses will tell you because we have Clinical supervision now erm that you know they're often you know heavy drinkers and heavy smokers and lots of other social problems and also because of the er you know the image of major surgery to their head and neck they have their own set of problems. Whereas patients, my patients, might have a colostomy and if they're having trouble I with that can sort them out now, but then I can refer them to their stoma nurses so it tends to be a very different set of problems. And I think that's the thing about this journey, the doctor will say yes this is where we want you to be but that route is really different for different patients isn't it?*

Nurse (CS08).

Although the journey metaphor was strong throughout the interviews, there was rarely mention of the destination. Only an allied health professional explicitly identified that part of the journey is to support death and dying:

*Well I think we walk with people on their journey of life of which death is part of it.*

Allied Health Professional (CS04).

### **5.4.2 Being there**

It would seem that given the unpredictability of the patient journey, staff perceived their role as one of simply 'being there', in supporting rather than leading the patient journey:

*I've got a couple of patients who say it's really good to know you're there, even if there's not a lot happening.*

Community Nurse Focus Group (CS06).

'Being there' suggested that staff were available if, and as, required. 'Being there' also implied a passive intervention, reflected in the term 'watch and wait' as a means of managing an uncertain prognosis and unpredictable care needs:

Participant 1: *I think they're told watch and wait. A lot of patients when they finish chemo or anything we're gonna put on the watch and wait scheme now.*

Interviewer: *Oh it is actually a term?*

Participant 1: *Yes, patients get that ...In some ways it's quite a nice phrase.*

Participant 2: *It describes what it is.*

Participant 1: *It does describe what it is 'cos what I get is we can't say it's going to be like this or it's gonna be like that can we?*

Community Nurse Focus Group (CS06).

### **5.4.3 'Managing' carers**

This theme addresses the study aim of how patients, staff and carers negotiate care decisions. Staff appeared to consider that carers could facilitate decisions around the 'patient journey', and had an instrumental role in supporting patient care; however, carers could potentially hinder care decisions. Staff therefore appeared to 'manage' carers but whilst 'managing' implies an explicit approach toward working with carers, the interviews suggest a more implicit approach. There were two activities to 'managing carers' including, 'mediating & safeguarding patients and carers', and 'recognising carer needs' and these are explored below.

### **5.4.4 Mediating & safeguarding between carers and patients**

Staff recognised that referral to hospice care had implications for carers as well as patients, and describe acting as mediators between carers and patients in supporting care decisions. For example, carers could often construe patient acceptance of the day hospice as 'giving up', particularly if patients had also rejected active treatment such as chemotherapy:

*I've had a lot of patients who've said well actually I'm glad I don't have to have any more chemo and it's ... that decision's made for them because to stop chemotherapy off your own back is quite a hard thing as well and the spouse is always there saying oh you've got to, you've got to, I don't want to lose you, I don't want to lose you.*

Nurse (CS02).

Staff encouraged conversations between patients and carers as a positive part of care planning but this was also challenging given the complexity of personal and family relationships and the emotional context of death and dying:

*And other times you have to have them to discuss it between themselves because it's ...we don't know what their relationships are like do we, really so they do have to talk to each other about it and some people in relationships don't talk about a lot of things at times.*

Nurse (CS09).

Paradoxically, whilst staff appeared to encourage carers and patients to discuss care and care needs, there was also an effort to provide space away from each other. Patients rather than carers attended the day hospice, usually arriving with volunteer drivers, whilst carers were encouraged to relinquish some of their caring role. The volunteer drivers encouraged carers to take 'time out':

*Yeah usually yeah and you just say to them put your feet up, have a snooze – 'I can't I've got' – and I say what harm is it going to do, I says if you go and have a snooze now for a couple of hours I say when whoever it is comes home you'll be so different and it's surprising sometimes*

Support staff (CS05).

Giving time out to carers offered the potential for creating space for patients to talk in an uninhibited manner about concerns, worries and thoughts about the future:

*Sometimes they just want to talk don't they, they don't want anybody to say anything, and they just want to get things off their chest that they can't say at home.*

Support staff (CS05).

Staff acknowledged that encouraging time out for carers might lead to a sense of exclusion; but in some ways, this provided preparation of what was to come:

*The difficulty with all of that is when the partner dies and sometimes bringing them [patient at day unit] here helps people [carers] have a little what it's going to be like and that can be*

*detrimental as well but ... so there are many things to that but in the end it's the patient that we're meant to*

Allied health professional (CS04)

Staff appeared to identify patient centred care, privacy and confidentiality as key priorities when discussing care and priorities with patients. Whilst this would seem an appropriate approach, this had the potential to inhibit open conversations for both patient and carers, particularly when the environment afforded little privacy:

*And you can go into some patients can't you, I mean this might be the same in nursing homes but in the home you've got you now the daughter there, the grandkids running around and that is a block to how much you can talk about and if you've got a room full of people, you know and that blocks the patient being able to maybe open up about things as well.*

Community Nurse Focus Group (CS06)

It is worth recording however, that at the time of data collection, some staff were working with patients and families with extremely challenging needs. There had been very intense and challenging situations requiring police involvement, and raising issues of safeguarding in which staff had to protect patients from carers. These experiences might reflect in the data that positioned carers as potentially problematic. The following account presents a further example of safeguarding, in which a husband wishes to support his wife at home, but is unable to accept how much care is required:

*But the tenseness of the ward nurses knowing that she wouldn't be cared for well at home ...he did not have the capacity to do that, even though he was willing, he was still not accepting that she was very ill, still wanting to trot off to work yet she dying in a number of days.*

Nurse (CS09)

This example illustrates some of the tensions in supporting carers who may provide a resource for caring and care decisions, but may also present as

problematic. Care rightly focused on patient wellbeing and confidentiality but this had the potential to exclude carers (and carers' experiences reflect this point in Chapter seven).

#### **5.4.5 Recognising carer needs:**

Although care was patient focused, there was clear recognition that carers might also have support needs, which if not met could impede on carer ability and willingness to support care decisions. Not all carers have the skills, knowledge or confidence to support someone at end of life with implications for patient choice:

*And who tells the patient that actually you know the carers is saying I can't do this... you know, whose wishes come top? Because actually if that person can't go home without the other person doing what they know... I think we underestimate what it's like for people to be facing managing death when they've never dealt with it before.*

Manager (CS10)

One manager reflected that caring for, and being cared for, are not necessarily clear binary positions and expresses this as a future challenge in the context of longer life expectancy, older carers and patient choice:

*I think you know with the ageing population with greater co-morbidities caring is only going to get harder isn't it and actually the people who are going to be caring are by the very fact that we're all living longer, going to be older so you know what's to say that you won't have a 90-year-old patient with a sixty-five or seventy-year-old carer?*

Manager (CS12)

#### **5.4.6 Summary of staff perspectives on 'becoming terminal'**

Staff conceptualised the patient journey as transient and unpredictable. 'Being there' allowed patients to find their own way through the transition to palliative and hospice care. How decisions around care were offered, discussed and

understood in ‘being there’ was however unclear. Staff acknowledged carer needs but the priority was to focus on supporting patient confidentiality and care. Staff therefore appeared to ‘manage’ interactions in mediating between patients and carers, whilst also providing space ‘time out’ from each other. Staff therefore regarded carers as both a resource and a potential problem in shaping patient care and decisions around care.

## 5.5 Staff perspectives on ‘responding to uncertainty’

This section explores staff perspectives of the final core category: ‘responding to uncertainty’ (interpreted as ‘coping with uncertainty’ for carers and patient participants) and is particularly relevant to the study aims of exploring how (health care staff) support choice and decision-making, and the role of end of life planning tools in facilitating future care decisions. Table 13 provides a summary of themes.

Table 13: Staff perspectives on of ‘responding to uncertainty’: themes and sub-themes.

Key Theme	Sub themes
Responding to uncertainty	Documenting choice
	Trusting intuition
	Understandings of hospice and palliative care

The theme ‘responding to uncertainty’ refers to staff concerns that care decisions may evolve as patients adjust to physical and psychosocial changes in condition. Planning tools offer a potential vehicle for discussion around future care decisions, but are described with some ambivalence as captured in the subthemes ‘documenting choice’ and ‘trusting intuition’. Understandings of

hospice and palliative care also underpin issues of choice and referral around future care. The first subtheme to be explored is 'documenting choice'.

### **5.5.1 Documenting choice**

The sub-theme 'documenting choice' captures staff reflections around the use of care planning tools and choice. Staff discussed a number of key tools advocated by the Gold Standards Framework (2016) in planning and coordinating palliative care needs, which were current at the time of interview. These were primarily the Preferred Priorities of Care (PPC)<sup>3</sup> tool to document care wishes particularly place of care; Advance Care Planning (ACP) to document care wishes and Advance Directive to Refuse Treatment (ADRT) to outline preference around particular interventions at a future time. Do Not Attempt Cardiac Pulmonary Resuscitation orders (DNAPCR) in which decisions are made that resuscitation may not be in the patient's best interest were also discussed within interviews. The hospice was also involved in supporting a study evaluating the Sheffield Profile for Assessment and Referral for Care (SPARC), a 45-item questionnaire which invites participants to score on a range of physical, emotional, financial and spiritual dimensions with the aim of signposting possible support needs and referrals, and this tool is also discussed in the interviews.

Staff identified perceived benefits to using planning tools. For example, Staff expressed that advance care planning directives were particularly useful for those patients with either a clear prognosis or illness trajectory, for example, motor neurone disease (MND), or with very definite wishes around care

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<sup>3</sup> The hospice nursing staff identified that although they did not use the actual Preferred Priorities of Care (PPC) document, the admission documentation did record future care preferences based on this format. It is also worth noting that during the period of data collection, the Liverpool Care Pathway (LCP, 2009) was a feature of heated debate in the public arena, however this was rarely addressed in staff, patient or carer interviews. This is surprising but may reflect that the LCP was utilised at the end of life and was perhaps perceived to be irrelevant in the early stage of the 'patient journey' within the day hospice.

preferences. The following example presents a positive outcome for a patient able to articulate preferences:

*I'm thinking of a young man who recently died with us who literally died on his feet and dying at home was absolutely essential and he talked about [dying] and he did die at home.*  
Manager (CS12)

Staff valued planning tools that offered a guide for 'difficult' patient and staff conversations. For example, the Preferred Priorities of Care document (PPC) enabled staff to introduce and focus conversations around future place of care, with potentially positive outcomes:

*The daughter wasn't aware what he wanted and as difficult as it was he actually felt better for it and she said Dad I'm so glad we've done this and within 2 weeks of him doing that he came in here and died but I think it gave him permission 'cos everybody was informed about his wishes*  
Nurse (CS02)

The hospice offered a specialist palliative care service, and yet some hospice staff expressed a degree of confusion regarding the purpose of some of the planning tools as illustrated in the quote below:

*Interviewer: The Preferred Priorities of Care I ask if they've [patient] ever seen one and some say no and some say no I'd like to get one where can you get one so erm I'm just a bit confused about that 'cos I thought that was something that maybe you introduced?*

*Participant 2: Do you mean information, not the leaflet?*

*Interviewer: Yeah information*

*Participant 1: We don't tend to use it.*

*Participant 3: I didn't know we had ...*

*Participant 1: Well it was ...*

*Participant 2: The original came out with the End-of-life Care Pathway didn't it so of course we're also in a situation where we're not using anything like that because of the change of End-of-life Care Pathway?*

*Participant: [Hospice] has got it's, is developing its own. "*

Community Nurse Focus Group (CS06)

The discussion above may also reflect the uncertainty regarding the discredited Liverpool Care Pathway. Nevertheless, one manager suggested a general level of confusion among health professionals with regard to end of life care planning tools, particularly Advance Care Directive to Refuse Treatment (ACRT), and Advance Care Planning (ACP) tools:

*I think again, there is a bit of confusion amongst professionals between the difference between preferences and wishes and an advance decision to refuse things*

Manager (CS10)

Do Not Attempt Cardiac Pulmonary Resuscitation (DNACPR) orders appeared to offer a clarity of purpose. One manager suggested that DNACPR orders presented a more straightforward purpose with a black and white response:

*Yes because it's (DNACPR form) comes in the post whereas where do you want to die that goes right to here, [heart] doesn't it so maybe that's the difference because you, you know we sign pieces of paper every day don't we and actually maybe if the GP sends it in the post it makes it, I don't know this is just my own thought, maybe it makes it easier because you get it, don't resuscitate me, sign it, ok, I've sorted my funeral out I'm not going to be resuscitated but actually where do you want to die, it's very final isn't it. I know a funeral's final; you probably think that's really hypocritical but somehow that's probably the last thing you're going to have control of isn't it.*

Manager (CS12)

Nevertheless, staff remained sensitive to the ethical issues involved in decisions around resuscitation, particularly where patients and families did not fully understand DNAPCR orders. For example, staff expressed concerns around the burden and unnecessary distress for carers in completing DNACPR orders as a proxy decision maker. Staff also questioned the value of proxy decision-making particularly where the possibility of cardiac arrest was low, or when patient and carer involvement could be overridden by medical 'best interest' decisions as the medic below outlines:

*It's a bit like resuscitation decisions in fact it's never their decision but I think they can be left feeling that they've made the decision but that's, that's 'cos as professionals we haven't done it right 'cos I hate the thought that people feel that but I know it happens.*

Medic (CS07)

How teams communicated decisions was a concern among staff. The community hospice nurses implied that there was little discussion regarding DNACPR decisions, citing that some patients received forms from their GP via the post:

*Participant 1: I've gone in and picked up the fallout from that with the older patients.*

*Participant 2: You know with relatives or patients to sign DNACPRs they feel they've made the decision, they've gone away and they feel that they've written their ...*

*Participant 1: Death plan*

Community Nurse Focus Group (CS06)

Communication systems between different service providers (hospitals, community services, hospice services) was regarded as problematic<sup>4</sup> and variable:

*Interviewer: Do you write the district nurses notes?*

*Participant 2: Occasionally*

*Participant 4: I tend to but ...*

*Participant 2: It's such a mess the district nurses' notes.*

*Participant 5: See there's a document in there, a Priorities of Care Document in the nurses*

*...*

*Interviewer: But you don't fill that in?*

*Participant 5; Not very often.*

Community Nurse Focus Group (CS06)

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<sup>4</sup> The recently introduced national programme to implement a collaborative electronic information technology tool forming part of current practice (Electronic palliative care coordination system, Public Health England 2013) was not in use at the time of data collection.

Staff questioned the value of documenting care decisions and planning tools, which did not communicate effectively across teams. Field notes from the non-recorded nurse focus group capture uncertainty around how and where ACP, ADRT and DNACPR forms communicated and recorded (possibly in hospital notes, or care plans or even with a solicitor) and how this could prove challenging if not readily available when care decisions were to be enacted. Staff were also mindful that not all patients were comfortable in planning their own care:

*I think it is for the people who are well organised and want to sort that out. I think in ... it feels much more uncomfortable when the future is uncertain and they're living with the uncertainty because I think the choices that they make can make it feel too real, personally. Erm and I don't know whether that's a good or bad way to think about it, I just think a bit like if you sign that dotted line then you know your future is sold whereas ...*

Nurse (CS09)

There was also staff ambivalence toward documenting patient wishes in 'black and white' in face of the unpredictability of illness and limited opportunities for patients to review. Three participants referred to a birth plan analogy in order to illustrate the futility of planning care needs when these may be unknown:

*But I suppose that's also the trouble with birth plans. I mean the only thing about my birth plan (laughing) it doesn't go to plan at all does it? You invest all this time and energy and it might be that people feel the same about this plan.*

Medic (CS07)

### **5.5.2 Trusting intuition**

Staff interactions with patients around referral suggested that staff preferred a tentative and intuitive approach when assessing patient readiness for end-of-life care discussions. However, field notes recorded at the time indicated that staff were encouraged to complete some elements of the PPC on admission

(particularly preferred place of death) in preparation for the subsequent multidisciplinary team meeting:

*Waiting to interview a patient in the day unit. Noticed doctor and nurse preparations for an MDT (multidisciplinary team) and some anxiety that a number of case notes had no record of preferred place of care or discussion around care needs. Seemed to be a bit of a panic as though this might be seen as a lack of care in the meeting.*

Field note dated 10-09-2013

Staff, however expressed disquiet that a discussion around PPC, at the time of admission was untimely and detrimental to the patient and the staff relationship:

*Yeah, yeah but I still, I don't think you know to expect to meet somebody for the first time and them talk to you about their advance care plan is a bit ridiculous really erm because a lot of people will want to get to know you. There's got to be a, it's about the relationship building and going at their pace and not thinking it's a bad thing to have to go back to some things.*

Manager (CS10)

Some questioned whether the prescriptive use of tools merely presented a quality measure to 'evidence' good care, rather than meeting patient need. C01 (unrecorded) was very forthright in asking 'who are the tools for?' and felt that documentation was more around managerial bureaucracy than patient care. Interestingly a manager also questioned the usefulness of advance planning tools, particularly for those patients wishing to focus on the here and now:

*But you know erm you know, the, the concepts are good but erm I'm not sure whether everybody wants to have a written ... I mean that's the other thing you know all these things like advance care planning the concept sounds fantastic don't they and we all sort of think oh yeah I should do that but the reality is very painful and it's also sometimes for people when they're facing a terminal illness they want to live every day as it comes anyway (laughing) so it's you know erm ...*

Manager (CS10)

Staff discussed their experiences of using the SPARC tool (see section 5.5.1). Two staff nurses in the day unit had experience of using SPARC and were positive around the opportunity to identify areas of patient concern and patient readiness to discuss future care. The staff provided an example of a patient identifying a sexual concern, which the team felt they would not ordinarily have appreciated as an issue for that patient:

*Yeah every new patient on the initial assessment is given a SPARC form and that identifies to us what their main concerns are at that time and then that gives you, I think, it opens a conversation because if you know I mean there's been issues around sexual dysfunction that you probably would not as a nurse routinely ask.*

Nurse (CS02)

Despite the enthusiasm regarding SPARC expressed by some, not all were positive. One nurse (SC09) felt that although the SPARC tool identified patient concerns, lack of time and skills required to address issues reduced the potential effectiveness of the tool. Another participant (CS09, who interestingly was involved in the development of SPARC), preferred intuition rather than SPARC in exploring care and decisions with patients:

*Just ... I think hopefully we talk to patients enough about what's happening to them, to get to know them a bit because we do cover most of those bases ...*

Nurse (CS09)

Intuition appears to offer a more 'common sense' approach in assessing patient readiness to discuss and plan future care and echoes the tentative process adopted by staff when referring patients to the hospice. However, a Manager (CS10) indicated that a pilot evaluation of SPARC had revealed some discrepancy between staff intuition and actual patient need:

*We did a small er evaluation with 2 of the community nurses several years ago...and they were both shocked that things that they decided the patient would not want to talk about the*

*first time they meet them, or that patients would not want to go there they were wrong every time and it really surprised them I think*

Manager (CS10)

In sum, staff were ambivalent regarding the use of care planning tools which might be insensitive, ineffectively communicated and which failed to capture changing patient priorities. Instead, staff valued the skills of intuition in building relationships and trust, though intuition has the potential for a subjective and possibly erroneous interpretation of patient need.

### **5.5.3 Understandings of hospice and palliative care**

This theme explores how staff understandings around hospice and palliative care impact on decisions to refer patients to hospice services and is highly relevant to the study aims of exploring how patients come to use hospice services and how staff support choice and decision-making.

Staff expressed that the term 'palliative care' was difficult to conceptualise and explain to patients. One referring nurse articulated that the word 'palliative' has its etymology in the definition of 'to cloak' and felt that this was apposite in describing the lack of clarity and range of understandings around palliative care by health professionals, patients and families.

*From when we teach it it's very vague, it's cloaking symptoms, pallier, cloaking the symptoms, it's all a bit vague.*

Nurse (CS09)

Staff with a remit for referring patients to the hospice also had variable perceptions of the service. Not all the referring staff had experience of the hospice and those that had, had not visited the hospice for a number of years and were unaware of current services. One referring oncology nurse for

example, reminisced about working at the hospice a couple of decades ago and described the then highly visible Christian presence as 'off putting':

*They wanted me to go and pray in that room in the morning and I said no, I don't believe in God, I'll stand there but I'm not going to participate and they said oh alright but still in the 1980s you had a prayer in the morning and that's not for everybody. I know it's different now but ... I mean it would put me off if I thought I was going to a religious kind of place. I wouldn't want to go.*

Nurse (CS11)

One Manager was also concerned that other referrers, particularly GPs potentially had little experience of the services offered by the hospice:

*I think it's, I think it is all dependant on gatekeeping erm by referrers and it will depend on the GP or the district nurses' perception of when particularly erm and what you do as to when they refer the patients.*

Manager (CS10)

At times, staff conflated hospice care with the Macmillan brand (which has a high media profile). Ironically, some staff described their role by using the more familiar Macmillan brand as illustration. There is a risk however, that in so doing, they may have inadvertently perpetuated misunderstandings around hospice services

*I think Macmillan, is generally more understood. I mean sometimes when I'm explaining my role and they just don't get what I do I say imagine what a Macmillan nurse is, oh yes, I know that, I say tis kind of a doctor version of that and people get that concept I think much more easily than palliative care ....*

Medic (CS07)

One manager also expressed concern that media debates around assisted suicide did not enhance public understandings of hospice care and palliative care generally:

*The public erm, we've got polarised arguments going on because we had the Liverpool care pathway which was killing people and we've got an assisted dying bill that people... and if you get the Daily Mail one day it will be you know they're killing people with this terrible pathway so we should be allowed to choose to die and then actual opposite ends of the spectrum so what's in between it and we kind of have to sort that out as a nation, what we think is important there.*

Manager (CS10)

At the time of data collection, the hospice management team were reviewing branding, marketing, and impact on public perceptions of the hospice particularly with regard to charity work and fundraising. However, there was a degree of uncertainty about how to construct and present the hospice positively in order to support fundraising activities, whilst also informing the public around services and endorsing a public health approach to death and dying. There was awareness of the negative public perception of the hospice as a place of death. To overcome fear of the hospice the allied health professional (CS04) described outreach work, which aimed to raise public awareness but also paradoxically, dissociated the hospice from death:

*Yes and erm and the statistics I often quote when I go to talk [to community forums] is and people get quite a surprise about this is that 40% of our patients who come on to the inpatient centre will go home. They look at me agog when I say it's as much as that because they just thought that everybody comes once and dies.*

Allied health professional (CS04)

There was also a tension between the need to increase awareness and widen access to services whilst at the same time manage finite resources:

*I think I've been around long enough to realise that's there is always room for improvement on that [access] but I also realise that if we were to get everybody, person who had the opportunity we wouldn't be able to cope and the waiting list would be worse than it is at the moment.*

Allied health professional (CS04).

#### **5.5.4 Summary of staff perceptions of responding to uncertainty**

Staff identified challenges to anticipating future care needs resulting in an ambivalent response to care planning tools. On the one hand, care-planning tools could initiate conversations and enable discussions around future care preferences, but if used insensitively were an intrusive formality, jeopardising trust and patient/professional relationships. There was concern around the effectiveness of tools in communicating across teams, as well as concerns around the lack of opportunity for patients to review should care needs and preferences alter. Staff therefore appeared to prefer intuitive approaches to supporting patients. Intuition however, is by its very nature subjective, with the potential for a subjective and possibly erroneous interpretation of patient care needs.

#### **5.6 Summary of staff perspectives of ‘Transition and Transience’**

The core categories of ‘being referred’, ‘becoming terminal’, and ‘responding to uncertainty’ underpin the central theme of ‘transition and transience’. Staff were mindful that the hospice signalled a transition to a non-curative condition, conceptualised by staff as the ‘patient journey’, with their role being supportive and non-directive. As a result, interactions around care decisions (including referral and future care planning) tended to be tentative and intuitive, with an emphasis on building trust and relationships. An emphasis on intuition and ‘being there’ however, can underplay the role staff have in actually ‘managing’ decisions. The following provides a number of key summary points:

- Staff engaged in a number of strategies, to ‘manage’ patient access to hospice care, including presenting the hospice day unit as a short-term day intervention and a focus on symptom control, particularly pain.

- Staff described access to services by BAME groups as challenging and were aware of the possibility that cultural assumptions could shape BAME access to services.
- Referral of older people to hospice services required staff to balance issues of co-morbidity, uncertainty of prognosis, and restricted resources. Referral to long-term care could potentially conflict with patient and carer perceptions of best place of care.
- Staff regarded end of life care planning tools with ambivalence. Tools were valued as a vehicle for identifying future care needs and encouraging conversations about future care, but also had the potential to impact negatively on the staff/patient relationship if used prescriptively, particularly where patients were unready to discuss or where care needs were transient.
- Staff questioned the practice of documenting choice, as opportunities to review were limited, communication systems across services were unclear, and needs difficult to anticipate with limited opportunities for patients to review.
- Rather than collaborators in care, staff positioned carers as either enablers or external to care decisions. Whilst carer needs were recognised, the key priority was patient autonomy and staff mediated between carers and patients to ensure safeguarding and patient focused care.
- Referral and future care planning was potentially undermined by mixed understandings by referring staff of what palliative care is and what hospice services could offer.

Overall the staff conceptualised their role as being part of a patient journey requiring a supportive sense of 'being there' as and when required. This may be an entirely appropriate approach to what is likely to be a highly emotional transition from curative care to palliative care. Nevertheless, intuitive and subjective responses have the potential to underplay the role staff have in 'managing' referral and care decisions. There are therefore questions around how staff assess patient need and refer, particularly in the context of finite resources, and referring staff assumptions about hospice services.

# Chapter 6: Exploring patient perspectives

## 6.1 Introduction and demographics

This second findings chapter explores patient perspectives of transition and transience. The findings explore how patient participants experienced access to the hospice in terms of choice and agency, with the aim of addressing the following:

- To explore how service users (patient and carers) facing end-of-life come to use hospice services;
- To examine how individuals make sense of choice within the context of palliative care;
- To explore the impact of ethnicity, age and gender on choice around hospice care;
- To explore how patient, carers and health care staff negotiate care decisions;
- Finally, to consider the role of end-of-life care planning tools in facilitating future care decisions.

Fifteen patients from the Therapies and Rehabilitation Unit (TRU) took part in one-to-one semi structured interviews. Chapter four provides further detail around data collection and a description of the unit is summarised in the footnote below<sup>5</sup>: Table 14 provides an overview of patient demographics. Chapter five indicated a lack of BAME representation in the data reflecting

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<sup>5</sup>The TRU provide medical support by way of reviewing care, social support through interaction with staff and other patients, or occupational therapy in the art room, complementary therapy interventions and physiotherapy. Attendance at the day unit was for one day per week, over a six-week period. Referral to the unit was generally via the local oncology unit or community services including General Practitioner (GP) referral. Patients were reviewed for discharge toward the end of the six-week period. Discharged patients generally continued to receive support from community teams, with the option of returning to the unit should the community team feel that they would benefit from a further period of attendance. Others might be encouraged to continue attending if on-going support was deemed to be necessary. Length of attendance therefore varied between participants interviewed. Some of those interviewed had also attended for a number of admission periods over the past year or so.

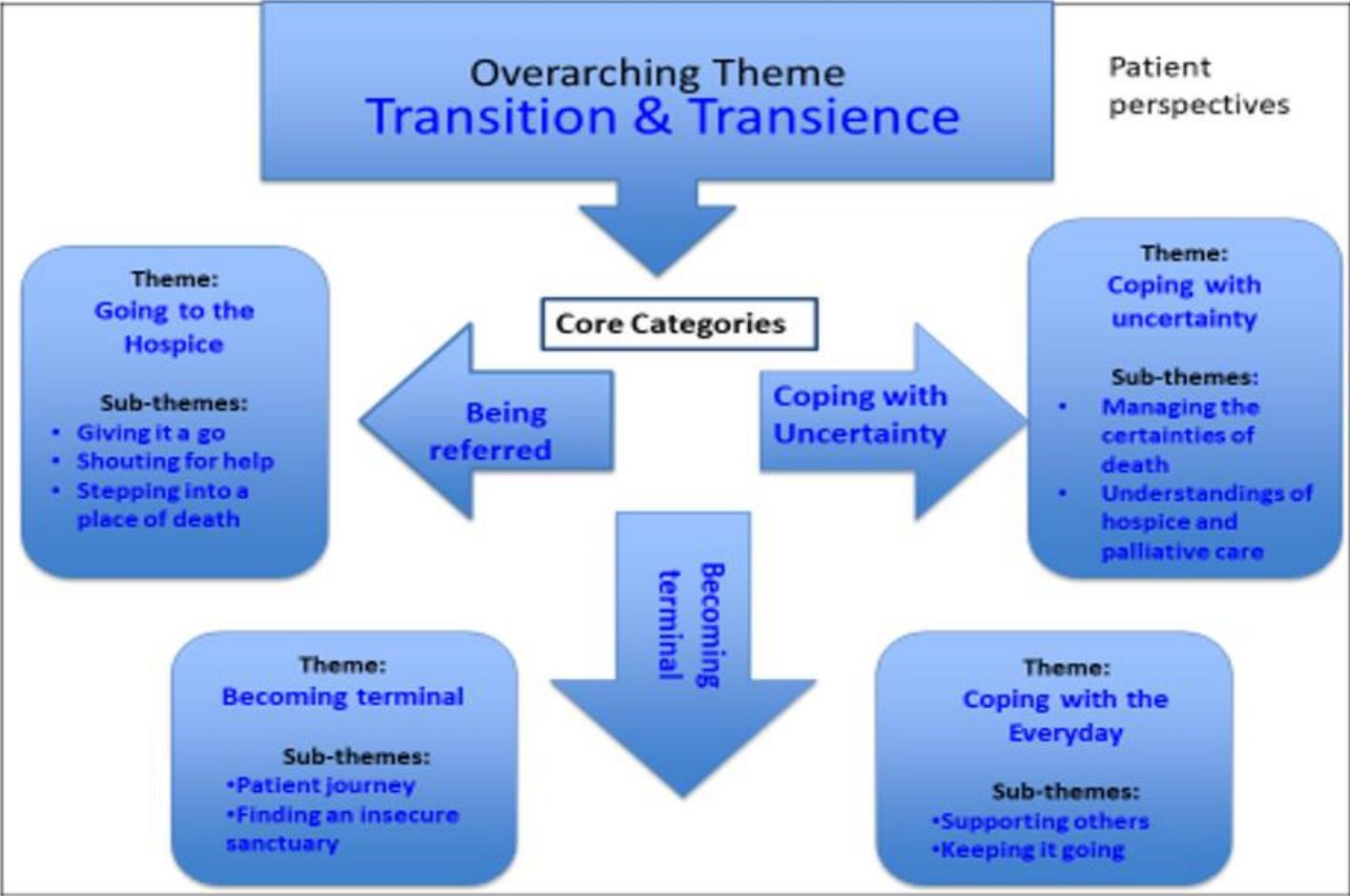
BAME use of hospices generally. Only three of the fifteen participants were male. Whilst gender and age may play a part in shaping experiences, participants themselves did not refer explicitly to issues of age or gender as influencing their experiences. Figure 16 presents the thematic framework of transition and transience in relation to patient data.

Table 14: Patient participant demographics

	Gender	Age	Marital Status	Living alone	Supporting role	Time at hospice	Referral Process	Receiving active treatment elsewhere	Advance care plan/PPC	Current focus	Any relative who died in hospice
1	Female	53	Single	Yes	Supporting mother	Two episodes of attending TRU and one stay as in-patient	Not sure. Macmillan or palliative nurse specialist or oncology sister	Chemotherapy	Approached but not 'right time'	Finance, and care package.	Yes
2	Female	70	Married	No	Supporting husband	3 months	GP	Physiotherapy and chemotherapy	No	Independent living	No
3	Female	73	Widowed	Yes	One son has support needs	3 weeks	Self	Chemotherapy	No	Independent living	Yes
4	Male	73	Single	Yes	Supporting mother	3 years-different sessions	Macmillan or district nurses	Active treatment elsewhere	'Booked' in hospice.	Will and funeral	Yes
5	Female	76	Widow	Yes	Recent caring role	3 weeks	Unsure	Chemotherapy	Not sure	Still sorting deceased husband's estate and a will for self	Yes
6	Female	82	Single	No	No	Past in-patient Currently attending for 4 weeks	District nurses	Active treatment elsewhere	Not sure.	Will and financial affairs	No

id	Gender	Age	Marital Status	Living alone	Supporting role	Time at hospice	Referral Process	Receiving active treatment elsewhere	Advance care plan/PPC	Current focus	Any relative who died in hospice
7	Male	57	Single	No	Supporting mother	2 weeks of 10 weeks. Previous admission 3 years ago	Not sure if oncology hospital, GP or specialist nurses	Chemotherapy	Not sure how you plan	Independent living. Part of campaign group against cuts to disabled people	No
8	Female	64	Widow.	Yes	Supporting mother and daughter	2 years 'off and on'	Self	Chemotherapy	Not ready.	Wills and legacy	Yes
9	Male	67	Married	No	No	5 weeks	GP or district or hospice specialist nurse	Support with existing long term condition	Not ready	Financial concerns and independent living.	No
10	Female	80	Widowed	Yes	Supporting brother	5 weeks	Consultant at oncology unit	No other treatment.	Prefers not to think about it	Will and estate	No
11	Female	57	Cohabiting	No	Recent caring role	6 weeks	Consultant	Chemotherapy	Takes one day at a time	Redundancy and independent living	Yes
12	Female	51	Married	No	Supporting husband and son	1 year- 2 episodes	Unsure	Chemotherapy	Takes one day at a time	Redundancy and independent living	Yes
13	Female	57	Married	No	Supporting mother and daughter	6 weeks	Unsure	No Declined further treatment	Not sure	Will and estate	No
14	Female	54	Married	No	Husband	9 weeks	Unsure	No	Not ready	Legacy	No
15	Female	44	Married	No	Supporting sons	10 weeks	Oncology hospital and specialist nurse	No. Declined further treatment	Discussed with nurses	Legacy	No

Figure 16: Patient perspectives on 'Transition & Transience': a thematic framework





## 6.2 Patient perspectives of 'being referred'

The core category 'being referred' specifically addresses the study aim of exploring how patients come to access hospice services. Referral is described in the key theme 'going to the hospice' and the subthemes of 'giving it a go' and 'shouting for help' illustrate how people come to access the day hospice. Table 15 provides an overview of themes and sub-themes within the core category of 'referral'.

Table 15: Patient perspectives of 'being referred': themes and sub-themes

Key Theme	Sub themes
Going to the hospice	Giving it a go
	Shouting for help
	Stepping into a place of death

Patient participants (patients) were referred to the day hospice via a number of routes, mainly hospital consultants, specialist nurses, community teams, or General Practitioners (GPs). Given the perception of the hospice as a final destination, it is interesting to explore how patients do come to accept referral. There appeared to be two distinct pathways; either passively accepting (giving it a go) or actively seeking (shouting for help).

### 6.2.1 Giving it a go

'Giving it a go' describes the reluctance of patients to accept referral. Decisions to accept were reluctant and usually driven by crisis, or trust in the referrer, or a lack of other options and suggests a rather passive acceptance of hospice services.

Patients were initially resistant to hospice referral, P14 (Patient 14, see table 14 above) for example, struggled with the speed at which her illness had

progressed and was reluctantly 'giving it a try'. Crises usually displaced resistance. P04 for example, was an older man living alone and supporting his sister (who later died at the hospice) and his elderly mother. Following a collapse at home, he felt he had 'nothing left to lose':

*The oncology unit referred me .....so I said I don't particularly want to be coming to the hospice, I'm quite happy.....I don't know, I didn't know anything about the hospice and you started feeling a bit, I don't want to go there, it's a bit, it might be my last lap... Then twelve months later when I collapsed at home they referred me again and I thought I've got nothing to lose. P04*

Others 'gave it a go' due to fear of the acute hospital. Whilst some could not say what it was about the hospital sector that frightened them, others cited previous experience. P01 required admission as in-patient for care and was offered a bed in the local acute hospital, the local oncology hospital or the hospice:

*She got me through to the palliative care Doctor and they presented me with 3 choices. One to stay at the (oncology unit), two to go to the (acute hospital)- I would rather have cut me legs off. P01*

Only one participant (P14) felt that she would prefer acute hospital in comparison to the oncology hospital or the hospice, but was unable to say why.

Some patients accepted referral based on their trust of the referring clinician (reflecting the emphasis on building trust, which was apparent in the staff interviews). One older participant in her 80s described a history of caring for her husband and had great faith in her relationships with doctors. Trust underpins her acceptance, suggesting a passive approach to decision-making:

*He said would you like to go. As I said to you before, I said I'll go wherever you send me I will go but it's the last place I'm going isn't it, and he said what do you mean? When I told him, he said no, it's nice, he said a lot of people like it, I said well, wherever you send me, I will go. P06*

Four patients had withdrawn voluntarily from curative treatment (primarily chemotherapy) but despite this, none had considered hospice services prior to referral. Instead they were 'giving it a go', usually following encouragement from a referring health professional who had emphasised the hospice as a place of creativity, 'a course' or day out (echoing the efforts of the staff in 'getting people through the door', see Chapter five).

*Yes, I just sort of ignored it and I wasn't ready for SL sort of thing. And she suggested I talk to the nurse about SL and I sort of said I don't want to go there and she said it is a really positive place and you will be surprised. P13*

### **6.2.2 Shouting for help**

Three women described actively seeking referral to hospice services. All had past experience of hospice services and, having been the carers for their husbands, they were keen to receive the help they had witnessed their husbands receiving. The three women were vocal in requesting hospice support and were highly articulate and equipped with the skills to support fact-finding (for example, P08 had worked in the technology unit of a library) as well as being familiar with hospice services:

*And you've choice. Your choices should be whether you need to go to [hospice] but you do need that information beforehand. I would have searched and I am capable of doing it, search the web, but a lot of people can't. And it's partly because of my job [librarian] I wasn't a wizard but nowadays more people have got their own access but we were always using direct. Gov.uk website. Trying to find the right places to go. P08*

The main reason given for requesting referral was psychosocial particularly for needs around low emotional state, and isolation and lack of an immediate carer, (rather than pain or physical symptom management). P03 describes how chemotherapy treatment left her almost housebound and her social isolation was key in seeking referral:

*Yeah, Yeah, it was about how I stopped being housebound. Because it was really starting to get to me, housebound. P03*

The request for referral was generally via a General Practitioner (GP) although this was not always initially successful and rebuffed. It is not clear in the interviews why. Resource management or a professional perception of need may have shaped GP responses although staff participants suggested that a successful referral trigger was likely to be one based on physical symptoms, particularly pain management (see chapter five). Rather than a shared process of decision-making however, participants actively sought additional 'back up' from the Macmillan advisory services in order to persuade their GP to refer to hospice services. There was disquiet as to when hospice care would be have been offered had they not already known the service, and concern regarding what this would mean for others without first-hand experience, as P08 reflects:

*I don't know when I would ever have got to Macmillan, well I do, probably when I had the bowel cancer in March and then I probably would have heard. P08*

Patients frequently used the term Macmillan to describe the hospice, when in fact this is a separate organisation and service. This misnomer may reflect in part the primacy of the Macmillan 'brand' within the UK (further discussion around understandings of hospice and palliative care will be explored in 'understandings of hospice care' below).

### **6.2.3 Stepping into a place of death**

Following referral, the day unit nursing staff contacted patients and provided opportunities for patients and carers to visit, as well as details of the service. Despite the recent visible attempts by the communications department to market the hospice as a service that added 'quality to life', patients perceived the hospice as a place to die. One participant described their first visit to the hospice as 'stepping into a place of death' and this feeling was common to all.

There was a strong sense in all the accounts of overwhelming 'shock' as they physically entered the building:

Interviewer: *So how did you feel that first day, that first you know, the night you were due to come in?*

Participant: *I was a bit jittery, little bit jittery....., a bit jittery because you don't know what to expect* P10

Most participants, either through visiting relatives and friends, or through charity activities, were aware of the local hospice prior to referral. However, as one patient who had previously acted as a senior manager in the inauguration of the hospice remarked, none had contemplated themselves ever having to use the service themselves. For those who had memories of visiting or caring for others there was high emotion. One participant described the emotion of returning to the building where her husband had died a few years previously:

*I was sleeping over there and my husband was fast asleep and I just went out on the balcony and watched fireworks going off and that was on new year's eve and he died in the January. And yeah that was odd looking at a view that I've looked at so many times that I've been here with him. .... erm and that was a bit hard as well.* P03

Part of the trepidation of going to a hospice may have been that referral acted as a clear signifier that they were dying as the following two quotes illustrate:

Interviewer: *What did you know about the hospice up until that point. What was your image?*

Participant: *Death. When you go in you don't come out.* P06

*They offer you a visit and you are apprehensive and you think you are being prepared (to die) and not quite sure.* P02

#### **6.2.4 Summary of patient perspectives of 'being referred'**

The hospice presented as a clear signifier of transition from curative to palliative care and was a clear reminder of the inevitability of death and dying. Those who actively sought referral were women with prior experience of caring for

others, and they were required to be assertive in pursuing referral. This may reflect a referral emphasis on physical needs rather than psychosocial need but does raise questions around who is referred and how. Accessing hospice services was however emotional for all patients, and the sense of shock was palpable, suggesting that enacting choice and decision-making is challenging in this context. Trust in the referring clinician, or a crisis driven referral suggested a passive approach to decision-making around referral, captured in the theme 'giving it a go'.

### 6.3 Patient perspectives on 'becoming terminal'

The core category of 'becoming terminal' provides an insight into the study aims around how individuals make sense of choice within the context of palliative care. Some of the data presented here appears at first to be secondary to the study aims, but the analysis is grounded in the data and the category 'becoming terminal' provides an insight into a patient's everyday priorities. These suggest that decisions about care primarily focus on 'coping with the everyday' rather than simply future care needs. Table 16 provides an overview of key themes and sub-themes emerging from the core category of 'becoming terminal'.

Table 16: Patient perspectives of the experience of 'becoming terminal': themes and sub-themes

Key Theme	Sub-themes
The patient journey	Becoming terminal
	Finding an insecure refuge
Coping with the everyday	Supporting others
	Maintaining independence

### 6.3.1 Becoming terminal

The theme 'patient journey' captures a transitional process of 'becoming terminal'. Patients frequently used the word 'terminal' to describe their status whereas staff did not use this term in the interviews, preferring the term 'patient journey'. 'Becoming terminal' captures the patient transition from a curative to a dying status. However, rather than a route through to a destination, the experience appears to be simply a state of turmoil. For P14, diagnosed with cancer just a year ago, it was a shock to find that (so she asserts) health professionals describe her as terminal:

*P: Yeah terminal lung cancer.*

*I: Did they actually use that word?*

*P: Yes, that's why I thought why I am shocked, 'what are you telling me'. P14*

The term 'terminal' signalled an unambiguous statement of dying:

*Interviewer: Do you use the word terminal. It seems a harsher word?*

*Participant: Yes they [boys] prefer the word terminal, not palliative. P15*

The journey of 'becoming terminal' appears to be an embodied transition with subsequent impacts on relationships and identity. P13 is clear that attending the hospice is itself a signifier of 'becoming terminal' and worries about the impact of this on her family, who are also struggling to come to terms with her decline:

*But then the thought of telling my family that I was coming was really worrying. Because they are now going to think I am going to die and it all made it very real. P13*

'Becoming terminal' is also an embodied state affecting body image and function. Typically, most were receiving strong opiate analgesia and there was much lethargy and effort involved in the interviews. Some also described the legacy of chemotherapy experienced as 'chemo brain' (although it is acknowledged that this phenomenon is not necessarily confined to those who

are dying but reflects that this cohort of patients were struggling with the side effects of chemotherapy) which contributed to an overall sense of deterioration:

*er chemo brain, forget so much, it's ... it's like having the slate wiped. It's strange. It's very strange. (P07)*

Bodily changes such as hair loss were also a visible signifier of becoming terminal to those around them.

*Cos my legs. I can't use them properly now, me legs. Well there are still stiff and it doesn't help that I fell in the car park as well cos I was that drugged up with all the drugs I just passed out and slid off the car. (P14)*

'Becoming terminal' also affected relationships. Therapeutic interventions, such as silk scarves and memory boxes made at the hospice served as both a legacy and talisman in a symbol to others that they were dying. Where family and friends did not appear to accept a non-curative condition, then 'becoming terminal' presents as a lonely experience. Seven participants had also experienced the loss of a close relative or spouse within the last 1-6 years, and bereavement compounded feelings of isolation and loneliness:

*Participant: You don't see me when I'm sitting on my own do you?*

*Interviewer: No, I don't see you in those moments. Those days are long are they?*

*Participant: Oh they are, yes. And I often don't see a soul you know all day and your mind starts going, well it does doesn't it, you're just sitting there. P05.*

The transition to 'being terminal' was also to witness the distress of others, adding to the sense of isolation particularly if those around them could not cope. P11 also appeared to feel ostracised by some:

*And then she'll get to our house; 'I'm not going in', he says, 'you bleedin well are'. She has to force him. I said look, 'I'm not contagious or owt like that I've got cancer, get on with it'. 'Oh alreyt he says. So he knows if I'm alreyt he'll be alreyt, but I've got to try and tell him that. P11.*

The impact of bodily changes and impact on identity particularly for example, the description of having a 'chemo brain' suggest a patient journey that is reactive and adjusting to change, rather than one of personal agency within decision-making processes. Nevertheless, there are examples of patient participants who made an active decision to withdraw from often-onerous treatments (particularly participants P12 to P15).

*Interviewer: So you had to have chemotherapy?*

*Participant: Yes three lots of chemotherapy. That is pretty horrible. Especially the first 3 months, so pretty horrible with it and I was very ill with it and I decided not to have any more. I could only manage 3 lots and luckily the CT scan showed it had stopped and the Drs were happy for me not to have any more. P13*

P13 reflected that transition from active treatment to hospice care was timely and found supportive therapies such as reiki more beneficial than acute treatment. For P15, who had experienced over 15 years of cancer treatment and remission, there was a determined shift toward rejecting onerous curative treatment and accepting a terminal status, and this decision was defended as not 'giving it up' but taking control:

*So I said I am not given up, I am still having that, I am just not having chemo, I had it once, I swore blind I wouldn't have it again. Thinking I would never have cancer again. And I want my hair back, I am fed up of walking about bald. I have walked about bald. With a bucket in front of you. And now I am terminally ill I want the life what I have got, as good as I have it. I want quality, not quantity. P15*

### **6.3.2 Finding an insecure sanctuary**

Trying to make decisions or negotiate care within the context of a physical transition of 'becoming terminal' was challenging. Even those who had decided to withdraw from active treatment experienced an initial trepidation of 'going to the hospice', however, the actual experience of hospice care offered a

surprising refuge and appeared to provide a sanctuary to cope with the transition of 'becoming terminal'.

The notion of sanctuary and refuge found within the data was interesting given the link between early medieval hospices, which provided immunity and refuge for travellers and pilgrims, and modern hospices. Nevertheless, most participants struggled with describing what it was that made attendance a positive experience. P12 articulates a typical response to my questioning around what the hospice offered:

*P: I really can't put into words what I felt, do you know what I mean. But it's totally different to what I thought.*

*I: What is different?*

*P: I can't put my finger on it. P12*

It did seem that the hospice seemed to provide a sense of feeling valued, and this could contrast against patient experiences of the acute hospital sector:

*That's what I hated about x hospital, well I thought they treat you as a piece of meat. They don't treat you like a proper patient. There is a couple who say that. P14*

Instant access to medical and nursing support was valued and details to food hospitality, provision of drivers, and therapeutic interventions such as reiki added to the sense of a sanctuary.

*Reiki, I think it's like the laying on of hands, its strange and like you know when they put hands near you and the heat and warmth, and you feel as though you are floating, and you don't think about anything you know..... No worries and no cares. P02*

Patients described a hidden side to the hospice, which was life affirming and warm, and being with people who 'knew'. Attendance offered an antidote to isolation with friendships becoming highly significant and described as

'musketees' or 'chemo buddies'. P01 cited friendships made as the most intense she had ever made:

*You make friends in here, deeper and surer and quicker than you make them anywhere else I have been. Because you are talking about deep things, life changing, and death. Yeah. You look after each other in a way that nobody looks after each other... P01*

A sense of transience and insecurity permeated the experience of the hospice as a refuge. Whilst all highly valued attendance at the day hospice, there was a dawning recognition that this was a temporary intervention. Patients were aware that attendance was only for a period of six to eight weeks and death was never far away. Importantly, friendships that were positive would later become a source of anxiety, causing grief and anxiety when 'buddies' died:

*Well we had a great plan, the four musketees, we were all going to be (at TRU) on the same day and we were all gonna come together on the same day and then (silence) then Betty messed it up by dying, Theresa messed it up by dying (tearful). And then in April my Chemo Buddy died. P01*

The threat of discharge and death also undermined feelings of security and added a sense of transience. Some were distraught as to how they would cope once discharged:

*No I was scared. I really didn't want to stop coming. Because when I am here, I am not at home I am sitting [thinking] this needs doing and decorating and all what I haven't got the energy to. And that's how I would be thinking. And while I am here I just enjoy it. P12*

One participant cried whilst recounting her experience of being told her first block of attendance had finished:

*And then the Nurse called me in and they had been discussing what to do...So she said don't worry about it, but she said they wanted a faster turnover. And I don't think that is a very good impression and that hurt. That took the caring side out of it. P08*

As a contrast, one participant was experiencing some unease as to why she was still attending after several months, worried that she might be 'worse' than she realised. Whilst all patients were apprehensive regarding discharge it is significant that none appeared to have actively engaged in discussing discharge plans and instead experienced a sense of unease.

### **6.3.3 Coping with the everyday**

'Coping with the everyday' is the second theme within the core category of 'becoming terminal'. This theme explores how participants invest in maintaining everyday routines. The work involved in coping with the everyday is relevant to the research aims around how individuals engage in care decisions. This theme captures the active involvement of participants as they negotiate the everyday activities illustrated in the subthemes of 'supporting others' and 'maintaining independence'.

### **6.3.4 Supporting others**

It was striking how many patient participants provided care and emotional support to others, despite their 'terminal' status. Eleven of the fifteen interviewed identified a direct or indirect caring role, causing sadness and worry for the future. As well as managing their own care, they were involved in providing for those around them. Care decisions often focused on others. For example, P13 as a 'sandwich' generation was supporting both an ageing parent and young adult, and P04 was supporting his ageing mother in a home, whilst P12 worried how to support her young son:

*Only trouble he has is sleeping which is a problem you know what I mean, he hasn't got a job. Erm I mean he has worked and he has worked nights and I don't know whether his brains not right, that is because he's not sleeping. But he went to GP and he was under a counsellor. He didn't tell me this, and I only found out because someone phoned up. And then his phone at bottom of stairs. And it was mums illness. So he is affected. It's me worrying about them more than they are me. It just breaks my heart to think, if I did go.*

*I Who's gonna look after them?*

*P Erm, that's what you think. You wonder who is going to look after them. P12*

Others were also supporting older relatives:

*Yes, so a lot on trying to sell the house [selling mother's home to pay for nursing home care] at the moment so that is just a mile from where I live. Really stressful. P13*

Interestingly holidays frequently featured in the accounts, and were important and highly valued in helping to support relationships. For example, P02 suggested that a break was highly important in sustaining efforts to cope with the everyday and spend precious time with each other:

*It's trying to find time together you know, to do things and of course we haven't had a holiday for two years because of all this. P02*

### **6.3.5 Maintaining independence**

Nearly all participants spent sometime in the interviews discussing the management of financial affairs, particularly where there were dependents. Despite the impact of illness and 'chemo brain' participants still had to engage in the worrying and stressful activity of sorting finances, redundancy, pensions and social benefits and care packages. One participant's sister was helping her to negotiate mortgage and credit cards but was dealing with employment issues herself:

*I'm trying to sort out this so I can have early redundancy on the grounds of ill health. I'm trying very hard to be patient because they can't find me form but yes, .....I only have so many weeks left, so if I don't get it done then I will get in to a position where I have no wage, and how do I manage then? P01*

Social benefits were challenging. P07 was undergoing a UK Government Work Capability Assessment scheme which would decide entitlement to disability

payments or advocate a return to work, and was anxious about his annual assessment.

*A great weight has been lifted off my shoulders er x rang me the day before yesterday and said I'm in the highest group of this new ATOS thing, so the personal independence payment, I'm in the highest group so I don't have to go for assessment. P07.*

Meanwhile P09 was anxiously awaiting a court appeal against the local Council regarding care costs and an overspend on his personal budget:

*Well they, the monthly budget was seven hundred and something pounds and erm they cut it down to four hundred and summat, so I had to pay two hundred and eighty and I'm still contesting it and they worked it out wildly wrong and they've already refunded me some and that is not the entire amount... which believe me, when you've got the problems that we've got that's the last thing you want to start messing with. P09.*

'Maintaining independence' captures the great efforts given to living day to day whilst also 'being terminal'. This involved not only financial issues and supporting others as above, but also reorganising accommodation, including extensions for access and particularly negotiating care packages.

Some accounts, particularly P01 and P09 describe social care services that were supposed to support home living, but were experienced as unreliable or of poor quality, causing emotional upset, fear and loss of control as their dependency increased. Liaising with care services to try to manage care needs was time consuming, effortful and distressing. P09 was late for a hospital appointment due to the ad hoc provision of care, eventually employing a friend but this resulted in an overspend in his personal budget as cited above. P01 described a paid carer who refused to address her by her first name, and another who made her feel vulnerable:

*Did try and she said, 'you haven't got any milk' and I said 'oh dear' and I will put the oven on and put your dinner in. And I was sitting there and I could smell something very strong and I thought what was that and it was gas. She had never operated a gas cooker so she*

*left the gas on. And I was getting funnier and funnier headed and it was because she had never operated a gas cooker. And she was only young, she was 18. P01.*

Patients also had to manage ongoing health issues. Although all had a diagnosis of cancer, many were also living with a number of co-morbidities and were receiving care and treatment at different centres across the City. P09 for example had been receiving treatment for multiple sclerosis for a number of years. Attendance at hospital appointments was onerous. P02, supported by her husband who drove to all appointments, described a typical week of hospital attendance, with only one day a week being free from appointments.

*So you know we are getting on with life we still meeting these friends and going for lunches which is nice. This one day a week we have. We take the opportunity to do it. P02*

### **6.3.6 Summary of patient perspectives on ‘becoming terminal’**

The focus on transition in this section illustrates that ‘becoming terminal’ is a transient and uncertain transition. Initially, patients resisted referral to the hospice but later the hospice was a refuge. However, as much as this was highly valued particularly in terms of psychosocial support, decisions around discharge did not appear to involve patients causing some unease, whilst death threatened friendships, contributing to an overall sense of insecurity.

‘Becoming terminal’ was an embodied transition, affecting identity and relationships. ‘Coping with the everyday’ therefore required active engagement in supporting those around them as well as maintaining everyday life.

‘Becoming terminal’ whilst maintaining independence, managing financial affairs and supporting others was highly effortful.

## 6.4 Patient perspectives of ‘coping with uncertainty’

The following section focuses on the third core category of patient perspectives of future care choices and relates specifically to the study aim around how patients, staff and carers negotiate and understand future care choices. The core category ‘responding to uncertainty’ captures the challenges for patients in engaging with an uncertain future. The subthemes, ‘coping with uncertainty’, ‘managing the uncertainties of dying’ and ‘understandings of hospice and palliative care’ are illustrated in Table 17 below.

Table 17: Patient perspectives of 'coping with uncertainty': themes and sub-themes

Key Theme	Sub themes
Coping with uncertainty	Managing the certainties of death
	Understandings of hospice and palliative care

### 6.4.1 Coping with uncertainty

This theme explores participant perceptions of future care as transient and uncertain. The interviews suggest that participants respond in a number of ways in order to cope. Lack of knowledge of care options as well as the perceived unpredictability of needs led to a sense of taking each day as it comes (mirroring ‘maintaining independence’). The future was avoided and a source of concern, as P08 who worried about being on her own, particularly given her experience in caring for her dying husband illustrates:

*In a way I would like to discuss it because it has been in the back of my mind thinking about the future and I suppose it's something I am pushing away because it's not something I want to think about. P08*

Given the effort in managing everyday concerns, it is not surprising that most patients coped with a focus on the everyday rather than the future, as P11 comments:

*Well, it's just thinking about the future isn't it, and when you've got this you don't think about the future, just think about everyday as it comes. P11*

Reflections on future care primarily focused around concern for others, suggesting a relational aspect to decision-making, particularly where there were younger people in the home. P13 has an only daughter who has just started college, and although she would prefer to be cared for at home her priorities focus on her family

*I know it's [death] going to happen but it is difficult for me to think about it. I would like to come here [hospice] because I think it is a lovely place and I think it would be good for the family to come here and I think they would be supported and it's not far from where we live. And friends. P13*

P15 was also supporting a young family and was concerned around home care and impact on the home environment and their welfare should she be cared at home:

*I told them that I want to come here and pass away here. My husband doesn't want it to be at home, he's frightened that if I got too poorly the boys would into the house and find me gone, and it would be frightening for them. Plus, I don't want my lounge to be my bedroom I would rather come here and have a proper bed and a proper hospital rather than laid downstairs. P15*

Patient responses to questions around future care priorities early in the admission process reflected staff concerns around issues of readiness and timeliness to discuss future plans. Staff broached preferences around future care as part of the admission process (reflecting staff data), but patients found

this too sudden and insensitive. P01 admitted to the in-patient unit on Christmas Eve, following a diagnosis and rapid deterioration was indignant:

*First time I came here, the nurse was unaware of how far I was down the spectrum and she said she used a question, which nearly killed me, 'How do you want to die'... [silence]. I thought you are kidding me; I don't want to die." P01*

One participant was flabbergasted at the thought of having to plan care when the future seemed to be beyond her control:

*How are you gonna plan your care when you don't even know what's gonna happen to you? Are they daft or what? P11*

Those with prior experience of caring for someone terminally ill were also acutely aware that decline and care needs were unpredictable:

*So it's like thinking ahead now. Knowing what I had to do with (husband) which is you don't know, you're going to be wanting, and I don't want carers. I didn't need any carers in so I don't know. And the stoma bag, who would deal with that. P08*

An unpredictable future added to the disquiet of formally documenting care wishes, again echoing findings from staff interviews. P06 had worked as a director of nursing and was aware of the agenda to document wishes, but was also vague around her own plans and where documented. She referred to the documentation as being the 'yellow pages' as if decisions had been made but not filed and not revisited, and it was uncertain whether she had access or desire to revisit the documentation. Similarly, P12 is vague around documentation of future care needs:

*I don't know. Cos I think someone asked that. Cos someone else came to talk to me at home as well and she asked loads and loads of questions. And I think it's all in the folder. What the SL nurse fills in and the district nurses have a folder when they visit and I think that's got about where you would like to be cared for. I don't know. P12*

In contrast, P15 discussed care needs on admission, which she described as useful in getting them out of the way (rather than an on-going dialogue):

*She said I want to ask you some questions and get them out of the way. So it wouldn't be brought up again which is nice. P15*

However, 'getting them out of the way' did not necessarily offer opportunities to review changing needs or wishes and there was general reluctance to document future care needs in black and white. P14 was clear in her directions:

*I said I didn't know. Leave that blank. So that's what they said, do you want to know. I said no, what's the point of knowing. You could drop dead tomorrow. P14*

Her response was also unequivocal regarding documenting her wishes around do not resuscitate orders:

*Interviewer: So were you happy to sign it?*

*Participant: No I haven't signed anything yet, I am not signing my life away! P14*

Finally, patients appeared to find planning for the future difficult, particularly where care needs may be unknown, unpredictable and transient, and care services unfamiliar. Consideration of future care needs primarily focused on those around them, rather than their own needs. Encouragement to formally document and record care wishes received a mixed response from apprehension, to indignation although for one patient the opportunity to document choices was welcome, suggesting that responses to future care planning are individual.

#### **6.4.2 Managing the certainties of death**

'Managing the certainties of death' focuses on the practicalities of dying, such as funeral planning and preparing a legacy. Whilst avoidance of future care planning could suggest a denial of death, it was striking that participants had

documented their funeral plans and wills in detail. Many also had first-hand experience of funerals and wills, for example, P04 had recently organised his sister's funeral and was planning both his own and his mother's funeral, whilst P02 had also recently organised her mother's funeral.

There was a sense that the practical elements of preparing a legacy were helpful for those left behind, particularly dependents. For example, P05 was recently widowed and described herself as 'obsessed' with preparing her will, to relieve the pressure on her niece. Likewise, P06 was anxious to leave a legacy to a friend who had provided care support, and P13 was keen to ensure provision for her daughter:

*She was looking at my hair and she said oh, you have made a will haven't you mum? And I said yeah I have. And she said what happens about the house and I said it would go to you are you're the only child and is in my name and my mums name cos of joint ownership P13*

Interestingly, discussion around Do Not Attempt Cardiac Pulmonary Resuscitation (DNACPR) orders featured alongside talk of funeral plans and wills, as if these were a further feature of the practical aspects of dying requiring attention. In some ways this echoed the staff findings that DNACPR orders were more tangible and less problematic to discuss (see chapter five) than future care planning tools. DNACPR orders appeared to be more acceptable to patients than ACP even where there was little opportunity to discuss. The bemusement of one patient who had not seen his GP for some time is apparent:

*P09: Not seen him (GP) for ages and it wasn't what I was expecting him to come out with.*

*Interviewer: "Were you given any information about what that would mean or ..."*

*P09: No, no. He just come out with that statement and I didn't particularly answer it one way or the other er it seemed a queer thing to say at the time that we arrived there. P09*

P10 was matter-of-fact around completing a DNACPR order, giving her age as a reason (80 years) and her response is in contrast to P14 who was some 30 years younger. It is not clear why DNACPR appeared to be a more acceptable intervention to most patients than future care planning. Possibly DNACPR reflected a further practical aspect of dying and death over which they were able to express control. Nevertheless, few seem to have engaged in a detailed discussion with staff involved.

### **6.4.3 Patient understandings of hospice and palliative care**

Patient understandings of hospice and palliative care underpinned referral and decision choices. Patient understandings of the hospice were generally unclear and conflated with other providers such as Macmillan, although three had some exposure through caring for others. Most were aware of the hospice through charity raising events, however none had anticipated they themselves would one day require hospice care, nor did such events appear to raise awareness of hospice services. For example, a number of those interviewed were unaware that the hospice offered a day unit and the actual experience of the hospice as a sanctuary contrasted with initial perceptions of a place of death. This led to a number of participants contemplating how the hospice could be presented or branded in such a way as to capture the positive aspects of the service, whilst at the same time recognising that the role of the service was to support those who are dying:

*Patient: Yes, as not being ... I think hospice ... there must be another way they can call themselves to take away the death thing. It's still going to be here you know. P07*

Some conflated the hospice with Macmillan services, particularly community services, and usually could not identify whether community nurses were from the hospice, or Macmillan or district nursing services. For example, P08 discusses how she 'got to Macmillan' but the service she is referring to was actually the hospice community service:

*I don't know when I would ever have got to Macmillan, well I do, probably when I had the bowel cancer in March and then I probably would have heard, or that's when I changed and got a Macmillan nurse so she would have. P08*

Such confusion is not surprising given that some participants accessed Macmillan services such as information helplines in the past. Moreover, staff findings (see Chapter five) indicated that some staff use the term Macmillan to illustrate their role and explain hospice services. The conflation of the hospice with Macmillan possibly reflects the primacy of the Macmillan 'brand' within the UK currently but may also reflect the association of hospice care with cancer.

Patients were generally unclear about what palliative care was. Definitions were unclear, with the word 'terminal' being used more readily than 'palliative' and the latter term appearing to be less well understood, and in the case below, anxiety provoking:

*Patient: But then they just put me on palliative care and I didn't know what palliative care were, I hadn't got a clue and I'm whittling my soul case out so I went on internet and it just said basically .....*

*Interviewer: Do you understand what palliative care is now do you think?*

*Patient: Yeah just basically you just go on and they keep an eye on you, that's basically all they can do. If you get worse they try and help you, if you don't get worse they'll just keep you on palliative care. It's that about hit and miss. I mean do the palliative care nurses know what palliative care is? P11*

Future decisions around place of care and palliative care needs were unknown. Even P08, who cared for her deceased husband at home, and who actively engaged in fact finding struggled to explore services and comments:

*I think it would be a booklet on the options, there might be something there, like a leaflet so something, like a bit of guidance not knowing things. P08*

Such reflections suggest that a range of factors including personal experience influence understandings around hospice and palliative care services.

#### **6.4.4 Summary of ‘coping with uncertainty’**

The core category of ‘coping with uncertainty’ captures that future care needs are perceived as unforeseeable, with ensuing apprehension and reluctance to document wishes. Rather than planning for an uncertain future, participants appeared to focus on the certainties of death, and attended to the practicalities of funeral and legacy planning as well as ensuring provision for close friends and relatives. Interestingly patients mostly regarded DNACPR orders as a practical and tangible part of controlling aspects of the future. Generally, understandings around palliative and hospice care were unclear and negative, and future care planning presented as challenging.

#### **6.5 Summary of patient perspectives of ‘transition and transience’**

Patient participant findings suggest that the hospice is a signifier of transition from curative to palliative care and death. However, rather than a linear process, the patient journey is experienced as an uncertain and transient transition. Coping with uncertainty leads to a focus on the certainties of dying and managing everyday living as well as maintaining independence. One of the most striking aspects of the patient experience was the role they played in supporting others. Generally, understandings around palliative and hospice care were unclear and negative, and future care planning presented as challenging. The findings therefore address questions of access and decision-making as follows:

- The actual experience of the hospice contrasted against expectations of the hospice as a place of death. Decisions to accept referral were initially resisted but driven by crisis and were reactive. Those patients with personal experience of services as carers were more likely to request referral. Reasons for seeking referral were associated with psychosocial aspects of care.
- Patients and carers did not appear to be fully involved in decisions about discharge leading to a sense of disquiet and insecurity, exacerbated by the loss of friendships. This undermined the sense of refuge gained from attending the day unit. The experience of the hospice therefore presented as an insecure sanctuary.
- There was a patient focus on maintaining independence and managing everyday issues, particularly supporting others. Decisions were therefore predominantly associated with social care needs, rather than future unknown health care needs.
- Future care needs were unknown and uncertain. There was also some misunderstanding around palliative care services. Decisions focused on the more certain and practical aspects of death and dying including funeral and legacy planning and providing for others.

# Chapter 7: Exploring Carer perspectives

## 7.1 Introduction and demographics

Chapter 7 will present the findings from interviews with carers<sup>6</sup> and will explore carer perspectives of supporting a family member or friend attending the hospice day centre or receiving hospice home care. The analysis explores the study aims of choice within the context of palliative care outlined below:

- To explore how service users (patient and carers) facing end-of-life come to use hospice services;
- To examine how individuals make sense of choice within the context of palliative care;
- To explore the impact of ethnicity, age and gender on choice around hospice care;
- To explore how patient, carers and health care staff care negotiate decisions;
- Finally, to consider the role of end-of-life care planning tools in facilitating future care decisions.

Staff and patient findings illustrate that referral to hospice services signifies a transition from a curative to palliative status, conceptualised as a 'patient journey' by staff and as 'going to the hospice' by patients (see Chapters 5 and 6). Carer perspectives capture a transition experienced as the 'end of the line'. Figure 17 provides presents an overview of the thematic framework of transition and transience in relation to carer perspectives.

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<sup>6</sup> A definition of carer based UK NICE guidance (2004) identifies carers as "Carers who may or may not be family members, are lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management" (See chapter 3).

This chapter presents the findings of six carer participants who provided support as a wife, husband or daughter. Only one patient/carer dyad took part in the study, and the husband agreed to a further interview following his wife's death (their experiences are in some ways the most vivid in illustrating the issues of transition and transience). C06 had attended a bereavement group and had cared for her husband at home with hospice support, but had never entered the hospice. The remaining four attended the Carers Relaxation Group, which ran weekly at the hospice day unit for a very small number of carers. Table 18 provides a profile of carer demographics.

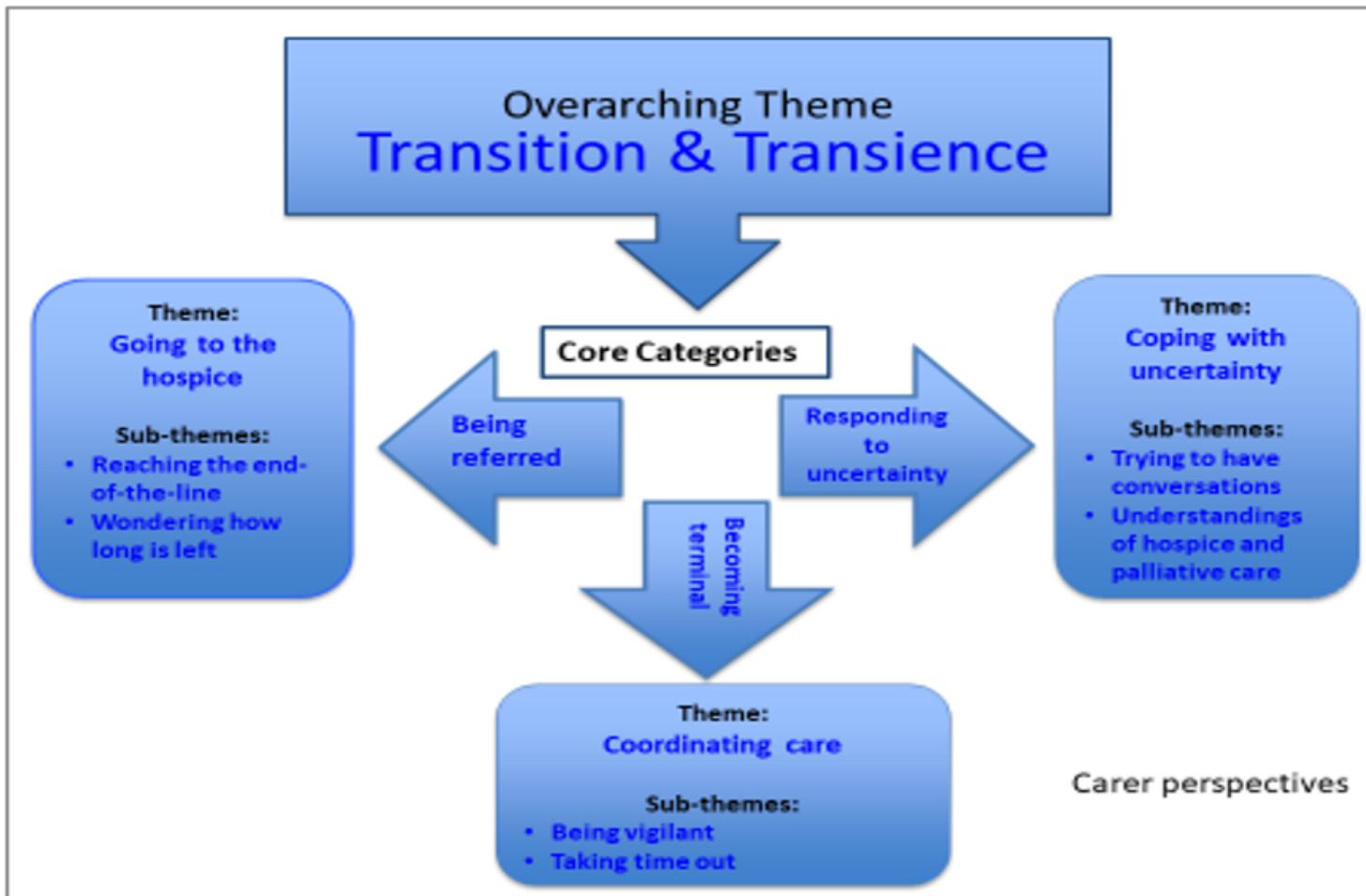


Figure 17: Carer perspectives on 'Transition & Transience'- a thematic framework

Table 18: Carer Demographics.

ID	Age	Recruitment route		Background	Individual requiring support	Referral process	Deceased family member
<b>C01</b>	70	Wife		Married 3 daughters	Wife	GP	No
<b>C01b</b>		C01 contacted researcher for follow up interview		Repeat interview 1 year post first interview.	Wife	As above	Yes
<b>C02/3 Joint interview</b>	C02 68 C03 56	Carer relaxation group		Married. Both have long term conditions	Mother	District Nurse	No
<b>C04</b>	75	Carer relaxation group		Married with daughter. Has mild dementia	Husband	Not sure. Currently inpatient	No
<b>C05</b>	58	Carer relaxation group		Married	Mother	Community nurse.	Yes (Bereaved 1 week prior to interview)
<b>C06</b>	69	Bereavement Group		Widow	Cared for husband	GP.	Yes

## 7.2 Carers Perspectives on ‘being referred’

The core category of ‘being referred’ specifically addresses the study aims of how people come to use hospice services and how patients, staff and carers negotiate care decisions. As in the patient accounts, ‘going to the hospice’ was a shock, and captured in the subthemes ‘reaching the end of the line’ and ‘wondering how long’. Table 19 provides an overview of themes and sub-themes.

Table 19: Carer perspectives on ‘being referred’: themes and sub-themes.

Key theme	Sub themes
Going to the hospice	Reaching the end-of-the line
	Wondering how long

### 7.2.1 Reaching the end-of-the line

‘Reaching the end of the line’ captured carers’ perceptions that referral signalled imminent death. Carers experienced referral with reluctance and shock and most were uncertain about the referral process. In contrast to staff interviews in which a journey metaphor described patient transition from referral onwards, for carers, referral signified that the journey (and some had many years of supporting care prior to admission) was about to come to an abrupt end. C01, was struggling to come to terms with his wife’s illness, and described referral as a fast track to the final destination of death and the impact was heartfelt and devastating:

*Well for me, I am on an express train, which is travelling at rush hour speed towards a black hole. B is my life, my very being*

C01 Supporting wife

There was also a sense in the carer accounts of betrayal that in accepting the hospice, their relative may have ‘given up’. C01 was almost bewildered that his wife had agreed to come to a place of death:

*Literally, I didn’t want to come. I **never** thought she would come*

C01 Supporting wife

Moreover, later:

*I'm thinking I'd sooner you [wife] would rather be with me than going to [hospice], I was very selfish and she was conscious of that.*

C01 Supporting wife

C06 and C05 however, were involved in the process of referral to the hospice. C05 had struggled to cope with caring for her elderly mother and felt the hospice would be supportive. C05 was a teacher of religious studies and was highly informed around the work of Cicely Saunders and the hospice movement. It is likely that this shaped her positive response to hospice care. She was involved in gradually introducing the hospice to her mother, and her experience mirrored staff accounts of working with carers to 'get people through the door', (see Chapter 5)

*It was just a step-by-step basis. The first job was to get her through the door, the second job as the relaxation, the third job was come for the day, and we'd only got to, she was due to come for a day.*

C05 Supporting mother

Carer C06 was also involved in the referral process however; she conflated both the hospice and hospital care and expressed antipathy toward hospital services. When the GP introduced the possibility of hospice referral, she refused on behalf of her husband but agreed to accept community hospice support:

*No, he [GP] asked me [re hospice care] so I said erm well he doesn't want to go in hospital.*

C06 Cared for deceased husband at home

Unlike the other carer interviews, CO6 had prior experience of providing end of life care for her first husband and again, unlike the others, she and her husband had openly discussed his preference to be cared for at home and she was determined to uphold his wishes.

## 7.2.2 Wondering how long

Despite the concept of the hospice as a rapid 'end of the line', there was surprise that the demise or discharge from the unit was not so fast as expected, leading to some speculation around 'wondering how long' until their relative died.

The hospice day unit was for one day per week over six weeks. For CO1 whose wife had attended for a few months there was great unease as to firstly why she attended for so long (the implication being she was sicker than realised) and secondly, increasing anxiety with regard to how they would cope following discharge:

*It [the day hospice] seemed to go on and on and I couldn't understand it, and then today is Bs last day. And that was a shock to me. It was a shock, because the question is why?*

C01 Supporting wife

CO2/03 were surprised that the journey had not ended as quickly as imagined, given their perception that referral indicated imminent death. C04 described looking after her frail older mother whom she assessed as being very end-of - life, but following referral to the TRU she exceeded their expectations:

*But she said that last Friday she enjoyed it you know she made a bracelet and the week before they'd done some tie/dye stuff and she brought this scarf and we were absolutely amazed weren't we?*

C02/3 Married couple, supporting mother.

The sense of wondering 'how long' and understandings of the hospice as the 'end-of-the line' would suggest that either carers were not involved in discussions around access to the hospice or future care planning or were not engaged in conversations in which they could voice their concerns.

### 7.2.3 Summary of ‘going to the hospice’

Only two carers were actively involved in decisions around the referral process and care, and both had prior understandings of the hospice and end of life care. Even so, carers’ expectations resonate with patient understandings of the hospice as a place of death. For carers, referral is experienced as devastating and includes a sense of betrayal that their relative may have given up. Their experience of caring for their relative often predates referral by a number of years and this may have contributed to the sense that the journey was now at an end.

### 7.3 Carer perspectives on ‘becoming terminal’

The following section explores carer perspectives of the core category ‘becoming terminal’. Perspectives are explored in the two almost opposite themes of ‘being vigilant’ and ‘taking time out’. Table 20 provides an overview of themes and subthemes relating to ‘becoming terminal’.

Table 20: Carer perspectives of 'becoming' terminal': themes and sub-themes

Key Theme	Sub themes
Coordinating care	Being vigilant
	Taking time out

#### 7.3.1 Coordinating care

The theme ‘coordinating care’ captures carer experiences of supporting someone who is dying. Most described their role as coordinator of care, which often predated referral and continued during the time of the interviews. This role required them to be highly vigilant but was exhausting and distressing. Being encouraged to take time out by staff, however benign the intention, jarred

against their highly vigilant role, and carers appeared to value receiving support rather than taking time away from caring. This theme also captures that carers were generally very involved in supporting care, but were less likely to be involved in making decisions about care.

### **7.3.2 Being vigilant**

For those carers interviewed, coordinating care required high levels of vigilance to manage the almost daily range of hospital appointments and services and to ensure that care was appropriate.

*But again dependent on Bs hospital appointment because I mean we've been going to a hospital 4 or 5 days a week regularly. We go to the (acute hospital) for physiotherapy once or twice a week. We'll go to the (other acute hospital) for checks and tests, and go to Oncology hospital Thursday and Fridays to see the professor and have chemotherapy treatment and we will come here one day a week.*

C01 Supporting wife

Parking at first appears as a superficial element to coordinating care, but there were frequent reference in the interviews to the effort of physically and emotionally attending appointments and services. CO2/3 provides an example of the challenges of hospital parking:

*He had phone call from security and I said oh aye, and she said you've been parked here a long time. I said I'm waiting for somebody in there; she's 84 I want to be on tap. He said its 10 minutes and I said I know I've been here quarter of an hour. He says, but, he were all right he said to me drive round block and come back and do you know what I mean. He said if you drive round block and come back that's allowed, because its only taxi drivers that's using it, and they park anywhere don't they so that what I did basically.*

C02/3 Married couple supporting mother.

Carers also described a high state of vigilance in ensuring information around health needs and care given was correct,

*She'd (social worker) been to see my mother twice and said that she were mobile and I thought where she was looking you know, because she's not.*  
C02/3 Married couple supporting mother.

C01 like C06 (who had promised to care for her husband at home) was wholly dedicated to caring for their partner:

*In terms of priorities, priority number one, top of the list is what happens to [B] what happens. Just caring for B].*  
C01 Supporting wife

'Being vigilant' was a commitment which C06 had promised to her husband. There was a strong almost territorial sense of presentiment in the way she described her role:

*I just said well, I say you can tell, you've just got a horrible feeling and I knew I didn't want to leave him either. I did not want to go shopping or do anything er you know I just wanted to be here all the time and as daft as it may sound I didn't want anybody else here either you know, and you can't tell your family that.*  
C06 Supported deceased husband at home

'Being vigilant' also included pain management. For example, C06 cared for her husband at home through to end of life with community hospice support. Pain management had provoked anxiety, both in making sure she had supplies: "Only thing I was frightened of running out of was the morphine" but also in her post death ruminations on whether in her administration of analgesia she may have contributed to his death:

*[Step daughter] told me quite categorically I'd helped her dad on his way and I said well... by giving him Drambuie with the morphine...No I think I*

*did, I think I did help him on his way because I helped him to die the way he wanted to, so I've said that to you now.*

C06 Supporting husband.

Similarly, C05 who was supporting her mother at home was also anxious and uncertain on how to support pain relief:

*... there was a night my sister and I were there, I'll never forget, and she was in pain and we didn't know what to do and we put the relaxation tapes on and I was lying on the bed in the room.*

C05 Supporting mother.

'Coordinating care' and 'being vigilant' was emotional labour and involved supporting others in the family as well as the ill individual. This could be challenging and stressful, with carers often acting as a buffer. Family tensions were apparent, for example, C05 talked about how decisions around care and money caused some discordance within her family and C02/3 who supported their mother had an undercurrent of resentment toward a brother who lived away.

*He can't, he can't really face it whereas I've had no choice..... but I do think he's finding it hard to handle, to face up to er he, does his bit from his end, he turns up for 2 hours once a fortnight, three weeks, if you need any money let me know and I'll buy her an electric wheelchair or something but there we go.*

C02/3 Married couple, supporting mother.

Carers displayed distress during the interviews, more so than patients suggesting, that emotions were high and that 'being vigilant' was a physically and emotionally stressful role:

*I remember, I mean I'm having problems with my memory, er nothing serious, I've had a brain scan and I've got one (laughing) and it's not dementia or anything, it's stress related, but I remember the district nurse telling us about it but I can't remember who referred us*

C02/3 Married couple supporting mother.

Despite high distress, carers continued to strive to maintain everyday normality. C05 for example, described trying to organise a break or holiday for her mother, which was a 'massive effort' organising wheelchairs, accessibility and so forth. In many ways, this resonates with the patient accounts of trying to maintain independence and 'keep it all going' to cope with everyday living. However, the experience of coordinating care and 'being vigilant' suggests that carers occupied a positioning in which involvement in care decisions was limited and unsupported by formal services.

### **7.3.3 Taking time out**

Carers were encouraged by staff to relax and take time out whilst their relative attended the day unit. Responses to 'taking time out' however revealed that carers struggled to relinquish some of their highly vigilant role.

Drivers encouraged carers to 'to take time out' and relax from their caring duties. Volunteer drivers were also valued in the patient interviews (see Chapter six), possibly reflecting that the volunteers bridged the gap between the hospice building and the patient and carer, usually being the only individual to link with the hospice day unit and carers. Being encouraged to 'take time out' was valued as a symbol of support:

*I very much appreciated the fact that they wanted to look after me too. Just that knowledge.*

C05 Supporting mother

Carers trust in the hospice increased as they observed their relative's response to the hospice, so that 'taking time out' became more acceptable. C05 for example, described how her mother would not mention the word cancer and withdrew in to herself but attendance at the day unit had a positive impact in just meeting people, particularly the drivers:

Participant: *It was the highlight of her week. Not kidding, erm meeting the people who fetched her*

Interviewer: *The drivers?*

Participant: *She loved them. She'd tell you all about them afterwards. She [community nurse] sold it on the grounds that it would give [name] a break, give me a break. .... She enjoyed the relaxation [relaxation tapes] of it and she went for it. I thought she would never go for that.*

C05 Supporting mother

As well as receiving support, the attendance of their relative at the day unit allowed space to relax from caring, knowing that their relative was safe. For C02/3 who were supporting an elderly mother, this was highly valued, '*It gives us a day off doesn't it but at least you know we can go out.*'

Being able to take time out was a gradual and transitional process underpinned by acceptance of the hospice and some relinquishing of the carer role. This was not the case for C01 (cited by his wife P02 as struggling to accept she was dying) however, and the opportunity to take time out was resented and not valued. He did not utilise the driver service, preferring instead to drive his wife and regarded the day unit as another appointment requiring vigilance. It was not until listening to an edited recording of her interview following her death that he recognised how positively she valued the hospice:

*B speaks very highly of the nursing staff. A pleasure that she enjoyed in doing the various activities, which were completely new to me. I wasn't aware that she had Reiki treatment and she had her hair done and she had her nails done and, and the work which she did in the handicraft section. The things which she made and the help which she was given to achieve those erm was quite wonderful and it's completely changed my perspective on [hospice]*

C01b Interview following wife's death

Some carers valued the opportunity to continue to care rather than 'taking time out' and appreciated hospice staff encouragement for their role as carers,

particularly when facing end of life care. C06 highly valued the community hospice nurse in giving her support, during her time caring for her husband at home in quite challenging circumstances and was not always confident she could cope:

*I thought I was going to turn the dining room into a bedroom and could nurse him at home but it wasn't to be because he wanted to stop in this room and [community nurse] bless her made it possible because she told me where everything could go, what I could shift, how I could shift it, the lot.*

C06 Supported husband

The opportunity to express fears around caring and feeling supported were valued:

*When I first came here to the carers, the first afternoon ,nobody else came so I had [therapist] all to myself and she asked me what my concerns were, my concerns were that I wouldn't be able to cope with whatever was coming.*

C05 Supporting mother

### **7.3.4 Summary of carer perspectives of 'becoming terminal'**

The experience of 'becoming terminal' captures the role of carers as highly vigilant coordinators of care, supporting pain management and managing everyday concerns. The hospice was a temporary refuge and gave permission to take time out. Not all carers however, were comfortable in 'taking time out', feeling that death imminent, and vigilance was high. Acceptance of hospice care was a transitional and individual process requiring trust. With regard to active involvement in care decisions, it would seem that carers were highly vigilant in coordinating care but were less involved in decisions or conversations around care.

## 7.4 Carer perspectives of ‘coping with uncertainty’

The final core category of ‘responding to uncertainty’ captures carer experiences and reflections on the future. This is captured in the theme ‘coping with uncertainty’ and the sub-themes of ‘trying to have conversations’ and explores the challenges expressed by carers in discussing future plans. ‘Understandings of palliative and hospice care’ also provides insight into how understandings of services influence care decisions, particularly referral. Table 21 provides an overview of the themes and sub-themes.

Table 21: Carer perspectives on 'coping with uncertainty': themes and sub-themes

Theme	Sub-themes
Coping with uncertainty	Trying to have conversations
	Understandings of hospice and palliative care

### 7.4.1 Coping with uncertainty

As in the patient interviews, plans that focused on the practicalities of death such as funeral planning appeared to offer some sense of control in the face of uncertainty. C05 discussed how planning her mother’s funeral prior to her death appeared to offer some comfort:

*She had a lot of what she wanted, she didn’t get everything and she had a really nice funeral. We worked really hard. ...she had left a list of things she wanted at her funeral which she did show me beforehand right near the beginning when she showed me her paperwork and she showed me her will then we put it away, she had done all that.*

C05 Supporting mother

The second follow up interview conducted with C01, which took place in his home, illustrated plainly the effort that patients and carers put into funeral and legacy planning. Following the interview, we sat and drank tea and he pointed to the large sideboard and described how his wife had set out thank you cards, as well as gifts and relevant florist instructions, which he was to trigger for all those who had supported her care in the last few years.

In patient interviews, DNACPR orders were associated with the practicalities of dying and there was a similar response in carer interviews. CO2/3 had an ageing mother and were matter of fact when discussing resuscitation, particularly in relation to age and diagnosis:

*P1: She doesn't want any. At hospital when she were first told it were terminal. She said I don't want bringing round*

*P2: Yes, she's very pragmatic in things like that, she said what's the point, I'm dying.*

*P1: I mean they did tell her at her age,*

*P2: What's the point?*

C02/3 Supporting mother

However, there was little discussion around future care wishes, and the couple appeared surprised when asked about future care:

*Interviewer: Has your mum made choices about what she'd like in the future?*

*P1: What do you mean?*

*Interviewer: Well, where would she like to be cared for?*

*P2 I don't think she's thought it about that way.*

C02/3 Supporting mother

Only two carers had engaged in clear discussions around future care. C06 was determined to keep the promise she had made her husband to care for him at home. C01 had also discussed with his wife who wished to receive end of life care at the hospice. Unfortunately, a sudden deterioration in health status

required admission to the acute hospital. A later request to transfer to the hospice was not possible due to bed availability. C01 recounted contacting his GP and the hospice for help, but she remained in hospital, leading to a sense of betrayal:

*I rang the GP but they were unable to help. Hospice said to me, again Pontius Pilate, sadly we don't have any jurisdiction over the hospital or have any means of achieving so it was all Pontius Pilate. And I'm thinking why? Don't they talk to each other? Don't they work with each other? Er and [name] thought the world of the NHS*

C01B Interviewed following wife's death

For C05 availability of services similarly challenged choice and control as her mother deteriorated over the weekend when there were no available beds. These latter two examples question the futility of choice around future care given the uncertainty of service availability and prognosis.

#### **7.4.2 Trying to have conversations**

'Trying to have conversations" reflects the challenges carers experienced in communications between carer and patient as well as health professionals. There was a strong sense that carers occupied a positioning that required them to care, and yet they were often on the periphery of care conversations (and possibly therefore care decisions). There was uncertainty around what they as carers felt they could discuss with professionals. C01 received a rebuff when requesting information from the consultant in front of his wife:

*Well I'm always apprehensive about asking the questions. At [oncology hospital] er when we saw [Dr] initially, I asked him a question and he looked at [B] and said do you want me to answer that.*

C01 Supporting wife

C02/3 felt ignored in care conversations and were anxious that their mother's health was worse than health professionals recognised. C05 who was

supporting her mother at home, also described how she tried to catch the palliative care nurse alone in the hallway, so that she could explore issues her mother may have avoided:

*I stuck around. Didn't usually participate too much 'cos as far as I was concerned it was mum's meeting and [nurse] just did her job telling mum*

C05 Supporting mother

Being on the periphery of conversations may reflect in part the emphasis in the staff interviews of prioritising patient confidentiality and person centred care in Chapter five. However, it is likely that 'trying to have conversations', added to the stress of caring and added to the sense of isolation apparent in some accounts. CO1 reflected painfully on his resentment and isolation at his wife's attendance at the unit.

*Because I would bring her and leave her and then what would I do with my day cos it's a hole. I am lost.*

C01 Supporting wife

Perceived lack of conversation with professionals often required that carers had to explore other sources of information to understand the care and condition of those they were supporting. C05 would wait to catch the hospice community nurses in the hall on their visits to the home, but was often thwarted and so turned to the internet for help:

*Participant: Does this mean she needs painkiller or just the pillow moved? I don't know. So ... but there were a lot of discussions we didn't have about progression of lung disease. I looked it up on the internet.*

*Interviewer: So you were supporting yourself really?*

*Participant: Yeah. Well you have to. I have to know these things but you couldn't discuss it with mum.*

C05 Supporting mother

C01 who was anxious about his wife's prolonged attendance at the hospice seemed reluctant to ask staff what was happening particularly around her discharge, citing an earlier rebuff (see above). C05 also commented that she was invited to phone health care staff to discuss her mother's illness but in the end did not, suggesting her mother was not ready to know, but this seemed to infer that she herself was left with unanswered questions.

*I was told endlessly by all sorts of different people you can ring me at any time, the doctors said that, the er palliative care, no the lung nurse at the hospital said that, I did ring them once or twice near the beginning. ... but I didn't ring them up and have conversations about progress of her lung cancer or that erm because she didn't want to know.*

C05 Supporting mother

Conversations between carers and family also appeared very tentative and difficult and C04 found conversations with her husband around the future challenging, and commented:

*Not... we don't talk about, I don't think we talk really enough about it because we're sort of like closing it away aren't we?*

C04 Supporting husband

### **7.4.3 Understandings of hospice and palliative care**

Understandings around hospice and palliative care services may constrain decisions around referral and future care choices. The staff and patient interviews suggested mixed understandings around palliative and end-of-life care and this was apparent in carer interviews. Responses to referral suggested a perception of the hospice as a place of death. All the carers were aware of the hospice through fundraising and charity work, however, as in the patient interviews, there was little awareness of the services on offer and none had been aware of the day unit or the therapies and rehabilitation interventions provided:

Interviewer: *So people had been mentioning the hospice to you for a little bit?*

P1: *In bits and bats and were just thinking don't want her to go there yet, she not ready for this yet.*

P2: *Yea but we didn't realise this rehabilitation went off.*

C02/3 Married couple supporting mother.

C01 expressed great isolation and found his wife's attendance at the hospice consolidated his feelings of distress. One year following her death he is able to listen to an edited version of his deceased wife's interview (discussed in Chapter four) and reflect. During this second interview he begins to explore that perhaps the hospice had not intended to exclude him on the days when his wife visited but at the time he was not supported in understanding the purpose of the unit and what it offered his wife. When asked whether he would have benefitted from carer support from the day unit he comments:

*It would have given me a greater insight into [hospice] because I've outlined what my initial reaction was, how it struck me rigid with fear and trepidation, how I described it as a house of death, quite brutally I think. Looking back to our conversation and listening to (B) since then has changed my perspective completely so perhaps it would have helped.*

C01B following wife's death.

#### **7.4.4 Summary of 'coping with uncertainty'**

Discussions around referral and future care decisions was constrained by the difficulties in communicating with health professionals (who may prioritise patient confidentiality) or finding conversations with their relative difficult, especially if the latter was unwilling to discuss. The future was uncertain, and there was a sense of lack of control. Sadly, where future care decisions included the hospice as a place to die, a bed was unavailable; suggesting that a lack of resources can thwart forward planning.

## 7.5 Summary of carer perspectives of 'transition and transience'

Generally, perceptions of the hospice as a place to die impinged on reactions to referral, and led to a dual role of taking time out and being highly vigilant given that the future was uncertain but death was imminent. In sum:

- Carers often supported their relative for a considerable period prior to referral, and referral was seen as the end of the line and devastating.
- Carers did not appear to be actively involved in the decision to refer or accept hospice services unless they had prior experience and knowledge of the hospice service.
- Disquiet emerged when death was not as imminent following referral, and suggests mixed understandings of the purpose of the day unit and palliative care.
- Carers acted as highly vigilant coordinators of care, supporting pain management, supporting others and managing everyday concerns. Carers appreciated being valued in their role as caregivers.
- Carers expressed some ambivalence, in that whilst they valued the opportunity or permission to take 'time out', they also expressed feelings of exclusion.
- Decisions focused on coordinating the practicalities of care including appointments and supporting others. Engagement with care decisions was less apparent and possibly inhibited by an apparent lack of opportunity to engage in discussion with health professionals, raising questions of carer support.

- Conversations with the cared for relative were also challenging, with uncertainty around what could be discussed and how.

Generally, perceptions were of the hospice as a place to die and the efforts required to manage everyday life reduced carers' capacity to engage in decisions-making processes and suggested a perceived sense of inevitability around the future.

## **7.6 Summary of staff, patient and carer findings**

By contrasting the perspectives of health care staff, patients and carers around the core categories of transition (being referred, becoming terminal, and responding to uncertainty), it is possible to identify areas of similarity and dissonance between the three perspectives. Accessing hospice services denoted a transitional shift from curative to non-curative prognosis. Staff, patient and carer accounts reflect that prognosis was unpredictable and therefore transition was less a step from one phase to another, but was instead a shifting and transient concept. Table 9 in Chapter 5 provides an overview of the three perspectives.

### **7.6.1 Summary of 'being referred'**

The notion of a 'patient journey' was a metaphor commonly used by staff to conceptualize their role in supporting transition. Staff identified that transition to hospice care was potentially highly emotional for patients, and seen to require sensitivity and tentative interactions to persuade patient participants to 'give it a go'. The journey metaphor articulated by carers conceptualised the hospice as the 'end of the line', indicating that the starting point of the patient journey preceded transition to palliative care. Patients themselves were less likely to describe a journey and more likely to focus on maintaining independence in the everyday whilst at the same time acknowledging transition as 'watch and wait'. Death was an explicit destination. If one were to develop the analogy of the journey, carers arrive at the station/hospice after a long and stressful journey and are encouraged to 'drop off', whilst patients await and prepare for the next stage, and health care staff provide the final mode of transport and destination.

Referral was a shock for patients and carers, and the hospice perceived as a place of death. Patients initially resisted hospice referral, and trust or crisis precipitated acceptance. Those that actively sought referral had prior

experience of hospice services. Not all carers interviewed were involved in referral discussions, and acceptance of referral evoked a strong sense that death was imminent and for some a sense of betrayal that their relative had 'given up'. Referral criteria were unclear but the staff focus on physical aspects of care such as pain management appeared to act as a practical strategy for encouraging acceptance of referral. This contrasted with patient emphasis on the need for support regarding the psychosocial aspects of care.

Staff acknowledged that cultural preferences and assumptions around care needs, the role of the family, language and cultural preferences could shape access to services for BAME groups. Older people with co-morbidities and uncertain prognosis required consideration of best place of care particularly in the context of funding concerns, and this had the potential for conflict between older people and family carers.

### **7.6.2 Summary of 'becoming terminal'**

'The 'patient journey' reflected an embodied experience of 'becoming terminal' with subsequent impacts on identity, relationships and care choices. Patient and carer engagement in decision-making was limited, and it is in this respect that staff presented their role as supportive and non-directive; however, 'being there' to support patients underplays the role that staff have in shaping referral, and responding to uncertainty and future care choices. 'Being there' also implies that patient and carers are passive in their responses to transition, but patient and carer experiences suggests that patient and carers are active in maintaining everyday independence and managing the practicalities of dying.

Both patient and carer perspectives of coping with uncertainty capture the sense that the day hospice provided a sanctuary from the efforts of everyday living whilst dying. However, both patients and carers recognised the sanctuary as insecure and transient as it provided a time limited service, and death was never far away. Patients (and carers) expressed a degree of disquiet regarding their use of the day hospice, and were often unsure how long they would

continue to receive the service or how and when staff would discharge them. This passivity and uncertainty raises questions around whether patients and carers felt they had a role in choice and decision-making but also captures the uncertain temporal nature of dying. Carers were highly vigilant in coordinating everyday care but were less involved in decisions and struggled to have conversations with health professionals and their relative around what was happening. This led to a degree of distress and reflected staff perceptions of carers as both obstacles and intermediaries of care. Staff findings suggest that that staff focused on a model of patient centred care, which addressed issues of confidentiality that carers experienced as exclusion.

### **7.6.3 Summary of ‘responding to uncertainty’**

Staff, patients and carers appeared to frame future care and choices within three broad approaches. The first approach captures the uncertainty around future care needs, the second focusses on the more certain aspects of death and dying, such as funeral planning, and the third captures a general lack of patient, staff and carer understandings of hospice services and palliative care. Patients and carers tended to focus on the more certain aspects of dying including the practical elements of funeral planning and providing for others, and this possibly offered a means of coping with uncertainty. Staff were also ambivalent around future care planning and whilst recognising that care planning tools could be empowering, they were reluctant to engage in a prescriptive process, which could undermine patient and staff relationships. Staff preferred intuition as means of assessing patient readiness to engage with future care planning. There was however a risk that this relied upon subjective judgement.

What was consistent throughout all three perspectives were the mixed understandings around hospice and palliative care generally and potential impact on responses to referral and future care planning.

The journey metaphor was a strong metaphor in the staff accounts and

provided a means for conceptualising patient transition from referral to death. Transition in the context of death and dying however, is transient, with great uncertainty around an unforeseeable future. Staff therefore appeared to prefer an intuitive 'waiting' approach to supporting care decisions but this belied their role in shaping 'the patient journey'. All perspectives captured that the transition to hospice care was an emotional signifier of death and dying.

The following discussion chapter will explore and contextualise the significance of the findings.

# Chapter 8: Discussion

## 8.1 Introduction

The overarching theme of 'transition and transience' captures the complexity of choice and decision-making. This chapter unpacks how choice and decision-making are understood in the context of access to a hospice day unit. In this chapter, I draw upon transition theory as described by Meleis et al. (2000) as a means of situating the findings within current literature and will explore the relationship between perceived needs, health literacy and choice. Transition theory will structure the subsequent discussion around the nature of transition to hospice care, the facilitators and inhibitors, and the responses to transition from the three perspectives of patient, staff and carer. I show that it is challenging to understand the processes leading to patient's use of hospice services and engagement in planning for their future care given the maelstrom of uncertainty and disruption that accompanies a shift from a curative to palliative care setting. This work also extends the theoretical work of Meleis et al. (2000) by examining the transient nature of transition. I emphasise that responses to transition are fluid given the transient nature of transition in the context of palliative care. This has implications for practice and future research, which I will present in the final concluding chapter. In line with SCGT, I will use the following section to outline my positionality as researcher within the discussion and analysis.

## 8.2 Repositioning the researcher

Charmaz (2006, 2013) argues that reflexivity offers transparency around data analysis and interpretation, and 'allows the reader to assess how and to what extent the researcher interests, positions and assumptions influences inquiry' (Charmaz 2013, p. 186). Numerous interactions shape the data, from access to the field site, to the semi-structured interview, transcription and coding of data and interpretation. It is not always clear to ourselves how we understand

another viewpoint, but it is likely that those aspects, which resonate with our own, lead us to project our own feelings, emotions and judgements on to others. The story told to some extent reflects 'the viewer as well as the viewed' (Charmaz, 2000, p.523). It is important therefore to outline my own positioning and possible impact on interpretation and subsequent discussion.

This study spanned a period from 2010 to 2017 with data collection occupying a number of transitions within my own life. Eschenbruch (2007) describes an ethnographic study within a German hospice in which he identifies as moving between 'insider' and 'outsider' within a system of multiple social interactions and networks. My own experience describes a similar course in moving from insider to insider-outsider, and finally to outsider. For example, at the beginning of this study my role in the hospice as a staff nurse and then a bank nurse was very much as an insider. As the study progressed, my position moved from nurse to academic and link tutor, to finally academic and researcher. A final positioning was the subtle shift from daughter to carer for my father.

I was aware (although not always clearly at the time) that my positioning as researcher, academic, nurse and carer shaped interactions, and those interviews which remain vividly in my mind's eye include those which resonate personally. For example, a patient expressed her distress at supporting her teenage daughter whilst at the same time coming to terms with dying, and her shift from nurse to patient. Whilst I was not dying, her account captured elements of my own biography, leading me to consider how far I was analysing my own reactions or responding to her unique experiences. I also empathised keenly with some of the frustrations of carers at a point when my interactions as a carer with health professionals was deeply challenging.

Being more receptive to certain aspects of data raises issues of bracketing and bias. However, as Charmaz (2006) argues, reflexivity enables an awareness of researcher preconceptions and interpretations. I was always alert to the possibility that transference of my own perceptions could influence the interpretation of data. However, the process of exploring data through coding and memoing, (a written process of exploring ideas around data, codes and categories, looking for connections and relationships within the data) along with

my reflections helped to clarify my analysis and retain an interpretation grounded in data. For example, my personal experiences helped to shape an understanding of the carers 'journey', as a highly vigilant role but one positioned outside of care decisions. I was careful not to superimpose my own experiences. The quest to look beyond our own horizons and explore taken for granted assumptions is a challenge, but mapping (diagramming, looking for relationships within data) and memoing, enable a deeper interrogation of data (Charmaz, 2006, p.111). The study aims to do justice to the stories told within the findings and contextualise them within current literature and theory.

### **8.3 Transition theory as a framework for discussion**

Using the framework of Meleis et al. (2000) model of transition, this study illustrates that transition to hospice services and reflections on future care is a transient rather than sequential journey. The findings were analysed in an iterative, inductive and deductive cycle in line with SCGT approaches. However, as Bendassolli (2013) and Timmermans & Tavoy (2012) assert, theory building in qualitative research requires a testing or application to existing theory in order to build and develop conceptual frameworks, described as abduction. Timmermans & Tavoy (2012, p. 179) describe abductive reasoning as a creative process, which challenges descriptive accounts and which captures features developed within data as well as extant theory. The process of looking for variance and 'surprise' within data and exploring this within extant theory offers a means of 'defamiliarisation' in which anomalies can be viewed against existing theory to provide further insights and thus contribute to theory development. The 'journey' metaphor particularly within staff accounts suggested a transition from referral to acceptance, with the ultimate destination of the 'good death'. In this study however, 'being referred', 'becoming terminal' and 'coping with uncertainty' captured a transient experience. This would suggest a need to reconceptualise the patient journey as one that acknowledges the fragility and uncertainty of transition in palliative care and requires a reconsideration of implications for practice.

Transition theory developed within the social sciences in the 1970s as a means for exploring continuity and change across the life course (Grenier (2012). Im (2011) cites the role of transition theory within nursing literature as enabling an exploration of how individuals adapt to new identities, illness and life stages, with the potential for identifying therapeutic interventions. Im (2011) argues that transition theory has been successful in developing mid-range theory within a range of health contexts, including migration, experience of menopause and transfer to nursing home care and attributes much of this development to the work of Meleis et al. (2000).

Meleis et al. (2000) describe transition as a move from uncertainty to a positive status of 'fully integrated identity' and 'mastery of new skills' and provides a conceptual model for exploring the domains of transition. This includes four domains, including firstly, a review of the nature of the transition; secondly, a review of the facilitators and inhibitors to transition (including personal and wider factors); thirdly, an exploration of patterns of response around acceptance and integration of self, and a final domain which provides an exploration of implications and appropriate interventions (therapeutics). Figure 18 details of Meleis et al. (2000) model of transition.

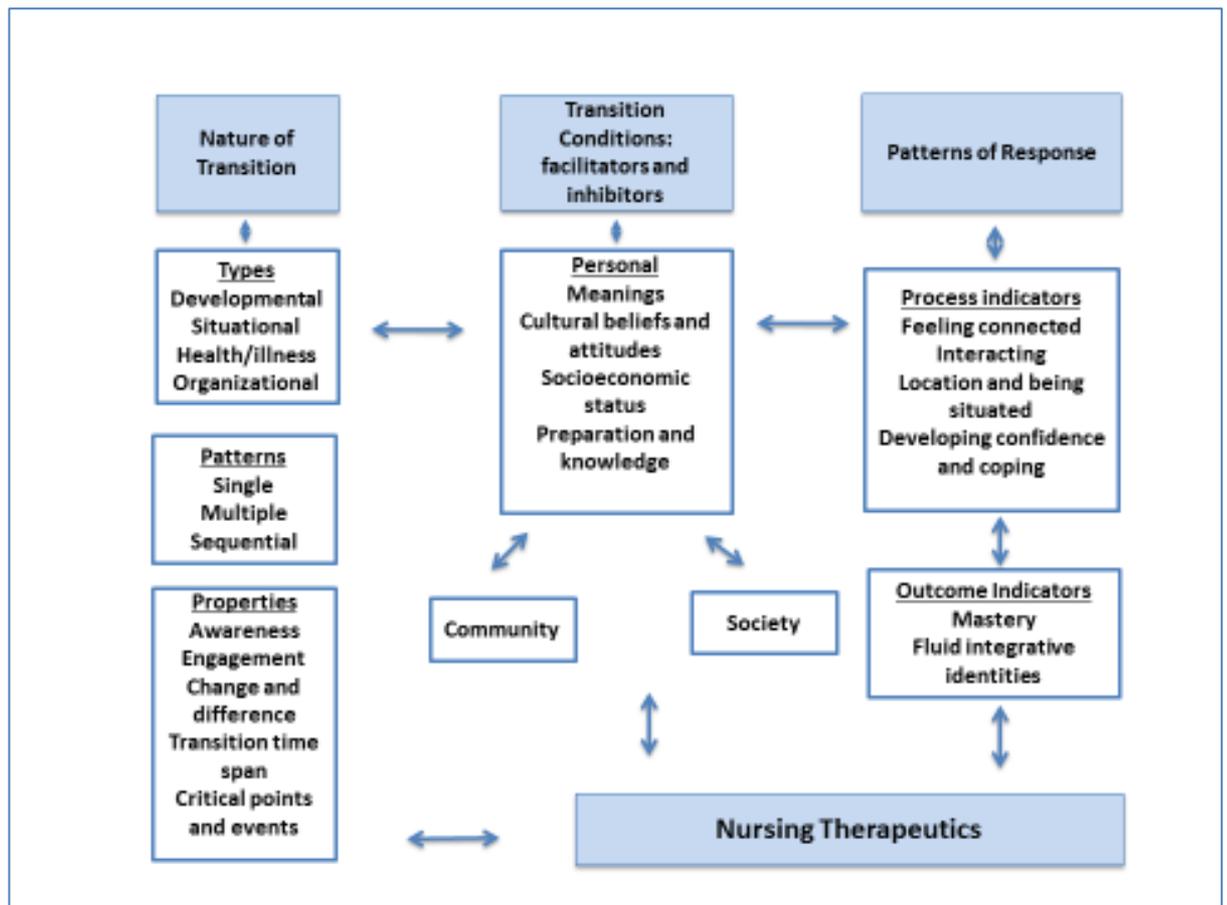


Figure 18: Model of transition for middle range theory (Meleis et al. 2000)

There is some critique of transition theory. For example, Grenier (2012, p.5) argues that definitions of transition “contain an inherent tension between fixed stages and fluid processes”. Grenier (2012) argues that in the context of ageing, transition theory has focused on individual, normative and ‘success based’ interpretations of ageing, rather than acknowledging the fluid nature of change and structural constraints. Davies (2005) explores transition theory in relation to older people moving to a care home setting and suggests that the individualised focus of transition theory omits the experiences of paid carers and the reciprocal nature of relationship centred care. Kralik et al. (2006) argue that transition theory offers useful insights but that studies are short term and therefore recommends further longitudinal studies in order to understand how people move through change over time. The transition model illustrated by Meleis et al. (2000, see Figure 18) identifies four domains with which to explore transition, including its nature, conditions, patterns of response and nursing

therapeutics. Whilst Im (2011) argues that the model adds clarity to transition theory, the categories and sub categories are less clear, leading to some complexity of interpretation. Meleis et al. (2000, p.13) do acknowledge that transitions are not unidimensional, but instead are unique, complex and multiple. Nevertheless, transition theory presents as a relevant framework for exploring the implications of the findings of this study and contextualising within current literature.

In the following section, I utilise Meleis' et al. (2000) model of transition as a means to explore factors shaping access to a hospice therapy unit with a focus on choice and decision-making. The first two domains of Meleis et al. (2000) model (nature and conditions of transition, and facilitators and inhibitors) help to illuminate how access to services is negotiated, and experienced. The third domain focusses on adaptive responses to transition in terms of acceptance and mastery. These elements are more challenging to identify within the context of this study, given that the journey or transition to hospice care has an uncertain destination (is the journey to hospice or death or both) and an element of temporal uncertainty (how long before destination). The third domain therefore captures responses to uncertainty and transience. The fourth domain of the model enables a consideration of therapeutics by way of implications and recommendations, and informs the concluding chapter. Figure 19 relates the application of Meleis' et al. (2000) model to the findings of this study and serves to frame the following discussion. The following section explores the nature of transition, particularly factors around the nature of transition and critical points.

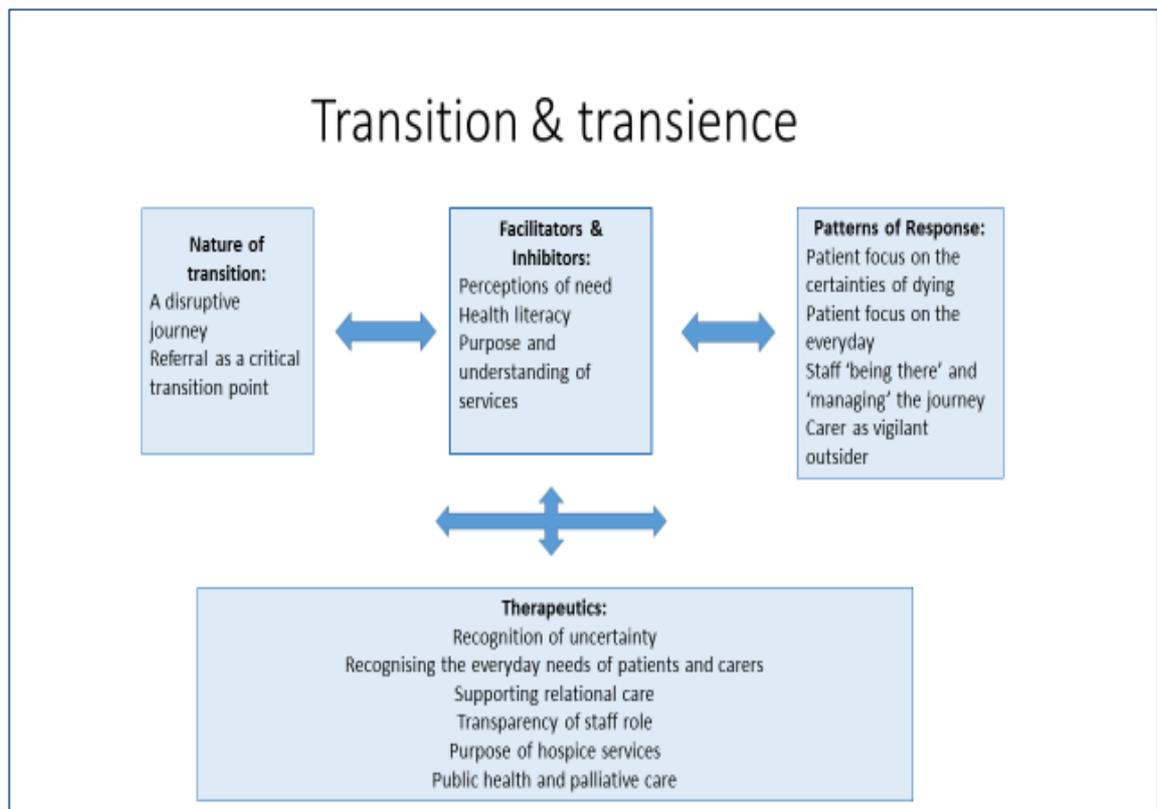


Figure 19: Transition and transience in the context of a hospice therapy unit.

## 8.4 Domain 1: the nature of transition as disruptive

The first concept of the model (Meleis et al. (2000)) focusses on the nature of transition. The journey metaphor employed by participants articulated an oscillating and transient pattern of transition, with multiple transition points and reflects a commonly used analogy within death and dying studies (Walter 1994; Mcilpatrick, 2007; O'Connor 2008), and within nursing literature (Barnard 2006). The journey metaphor is also prevalent in palliative care policy literature, in which the terms 'patient journey', 'pathways' and 'trajectories' feature widely, (see for example, Paget & Wood 2013, and '*Ambitions for palliative and end of life care*', National Palliative & End of Life Care Partnership (2015)). Lamprell and Braithwaite (2016) describe the 'patient journey' as a 'compelling' concept in terms of providing insights into care for service providers and being 'overdue' in terms of informing care. Current emphasis on personal engagement in decisions around palliative care can be traced within the pivotal work of Seale

(1998) in the revivalist interpretation of the 'good death' as one in which dying people 'participate in the construction of the caring team as 'joint adventurers'. The use of the journey metaphor by participants therefore captures the transition from curative to palliative care, symbolising not just a shift in terms of the context of care but also a liminal shift from a living to a dying status.

It was clear in the highly fraught and emotional responses of patients and carers that the hospice was a shocking signifier of death. Referral to the hospice represented a critical transition point, and signified a profound disruption of self. Grenier (2012, p.38) in discussing transition refers to the work of the early anthropologist Van Gennep (1909) in which transition is associated with liminality; a being between states, and involving three stages of symbolic death, liminal disorientation, and finally an emerging identity. In many ways, the hospice therapy unit itself represents a rite of passage, rather than a clear destination, echoing the work of Froggatt (1997) and building on the work of Hockey (1997) in which the hospice care is conceptualised as a space for liminality and transition. It was interesting that many described making silk scarves for relatives and friends, in an almost symbolic gesture that they were shifting toward a dying status if not a social death.

The disorientation and liminality captured in the accounts resonates with the theory of biographical disruption. Bury (1992) first explored biographical disruption in relation to chronic illness, capturing the dissociation of self, identity and relationships in the face of a shift in health status and ensuing uncertainty around the future. Annandale (2014) further examines biographical disruption in the work of Carel (2014) and Franks (2002) describing biographical disruption as a fracturing of the self, summed up by Carel (2014, p.73) in the following: "all the rules that governed my life until now have been radically broken and nothing remains the same". It is likely that the 'patient journey' presents as a disjuncture that challenges the capacity to engage in choice and decision-making.

Biographical disruption may partly account for the lack of individual engagement in care decisions (Cottrell & Duggleby, 2016). Patients in this study did not

experience choice as an active process of informed decision-making but rather as a reactive response to crises. The decision to accept hospice care or plan future care was certainly challenging for patients and carers, particularly those with no prior experience of hospice services. Media presentations of the 'good death' capture elements of individual autonomy. David Bowie's 'Blackstar' album presents an exemplary example of the expression of self-determination in death and dying. Boyce (2016) however suggests such themes were part of Bowie's life work. It is debatable how many 'ordinary' individuals are able to engage in their own dying as a form of self-expression and agency and as Seymour & Ingleton (2008, p.196) suggest, for most people it has never been expected or anticipated that they would plan their own care. It is also noteworthy that most patients and carers could not identify clearly who had instigated referral, suggesting either that disruption or shock affected engagement with decisions, or that there was little engagement in decision-making (or both).

It is unsurprising, given that the hospice represented a place of death, that referral was initially resisted. Acceptance was captured in the theme 'giving it a go' and implied an element of resignation echoing the work of Fisher et al. (2011) in which hospice inpatients perceived hospice care as a necessity (rather than choice). MacArtney et al. (2015a) identify similar themes in their work on hospice transfer in which resilience (in the sense of keeping going and preserving integrity of self) along with negative understandings of hospice care created resistance to all that the hospice signified (death). Crisis and trust in the referrer influenced patient acceptance of referral in this study. This echoes the work of Heyland (2006) in which patients ranked trust in the referring clinician as a key priority in end of life care planning. Froggatt (1997) in presenting the hospice as a rite of passage, suggests that the relationship between patients and professionals is one of parent/child, and in many ways this echoes the persuasive role that staff in this study presented in terms of 'getting people through the door'. Certainly the staff theme of 'being there' captures a tentative (if not parental) role) for staff in supporting the patient journey, suggesting a tacit acknowledgement of the disorientation and shock faced by patients as they entered hospice care.

It would seem that timeliness (as identified in the literature review), is an issue. Patients and carers in this study constructed questions around future care at the time of admission as insensitive, resonating with factors around biographical disruption. Barbour (2011) in the context of social work, similarly cautions that endeavours to meet prescriptive and sometimes bureaucratic demands around quality and professional practice, can be interpreted as 'people processing', whereby patients and carers are encouraged to fast track to an 'accelerated biography' which is often difficult imagine or accept. Without patient acceptance, untimely attempts to engage in choice and decision-making are likely to be experienced as insensitive and unhelpful. The findings of this study however also capture some ambiguity in patient responses, as whilst patients found premature conversations insensitive they also expressed disquiet in wondering when staff would broach conversations about the future. Given the sense of disruption on admission to the hospice, earlier discussions prior to deterioration may be helpful, and as Murray, (2017) asserts, early conversations may be timelier and cause less distress than anticipated. Certainly, there is a move within palliative care toward a public health model (Kellehear & O'Connor, 2008; Kellehear, 2013) and earlier conversations around future care needs prior to or at the same time as initial diagnosis (Murray, 2017). The work of Hannon et al. (2017) similarly concur that disruption may be minimised with earlier interventions based on palliative care.

Carers in this study similarly expressed a sense of disruption in the transition to a hospice, given that referral signified an acceptance of palliative care, and by default death. The transition to hospice care appeared to predate a number of years of supporting and coordinating care, and represented the 'end of the line', often with carers wondering 'how long' was left. Carel (2016) in a phenomenological exploration of death and dying argues that for those left living, the experience of dying is loss. This resonates with the carer responses in this study, in which there was strong sense of disorientation and distress reminiscent of anticipatory grief. The carers interviewed also expressed a dislocation of role in that having acted as key coordinators of care, they were less involved in the hospice day unit. Few were involved in decisions in

accepting hospice care, or involved in care decisions. There was evidence however that for some carers, acceptance was an act of betrayal and symbol of 'giving up'. The negative reaction of carers regarding referral may reflect that carers were not involved in discussions around care, and were themselves experiencing a disruptive transitional shift from role as wife, daughter, and husband to carer and bereaved within a form of anticipatory grief.

To return to Meleis et al.'s (2000) model and domain one, the 'nature of transition', it is clear that access to the hospice day unit is a critical transition point which is disruptive, uncertain and imbued with presentiment. Such a welter of emotions challenges choice and decision-making and raises questions around which choices are available and when.

## **8.5 Domain 2: Perception of need as a facilitator or inhibitor of transition**

The second domain of the Meleis et al. (2000) model focuses on the conditions of transition, particularly the factors that inhibit or facilitate access to hospice day care. These are discussed in two sections, firstly in terms of perception of need, and secondly in terms of health literacy.

An exploration of perceptions of need across the three perspectives (patients, carers and staff) provides a further means of exploring access to hospice care. Bradshaw's (1972) work advanced a typology of need in health and social care, which has been utilised in a number of studies including Cobb (2001) and Tanner (2010). Bradshaw (1994) describes three broad concepts around need including normative (bound by expert or professional interpretations of need), felt (perceptions of the recipients of care), expressed (demand for a service) and comparative (equality in provision). Need as a concept presents at both a macro and micro level. Macro level perspectives require a balancing of needs around resources, funding and policy and societal understandings of death and dying, whilst micro level perspectives require a balancing of need based on interpersonal, professional and normative requirements. Cobb (2001) suggests

that a typology of need can explain potential sources of dissonance between those in receipt of care, and those providing care.

### **8.5.1 Staff perceptions of need and older people**

For staff, the focus on supporting 'a patient journey' and 'being there' complements a patient centred focus within service provision (Lampress & Braithwaite 2016 and Baron 2009). However, this study suggests that normative perceptions of need underpin the persuasive role that staff have in 'managing' the patient journey. Despite the model of person centred care, which is particularly rooted within palliative care, Cobb (2011) argues that organisational, and professional agendas can coexist to shape a power relationship which, however benevolent, serves to sanction and legitimise 'need', and therefore control which services are offered, when and to whom. This raises a question of whether person centred care and the prescribed patient journey is in reality a 'systems centred' model of care.

Referring staff from the local oncology unit indicated that the discharge of frail older people required consideration of prognosis and care needs. In this study, seven of the fifteen patient participants were over 66 years old, suggesting age itself was not a barrier to hospice services. None however, had issues of dependency, frailty or dementia. There is however, growing evidence that palliative needs are overlooked in older people (Holloway 2009 and Ryan 2012), particularly in those with co-morbidities such as dementia where there is a more unpredictable prognosis and a perceived possibility of greater demand on resources (Albers et al. 2015). Referring staff cited that differing perceptions of need for frail older people caused discord between staff, patients and carers, particularly where the hospital team felt that a care home setting rather than a hospice would be the most appropriate means of meeting the needs of the older person( as well as managing resources effectively). This assessment could contradict the wishes of carers and the older person who assumed hospice care would best support their needs. The *'Fifth Report of End of Life Care'* (House of Commons 2015) also cautions that frail older people with long-term needs are often directed toward long-term care facilities, and may have to self-fund

following a financial assessment. As a result, the report argues that many older people are unfairly obliged to fund their own palliative care, serving to add further discord between families and professionals. How society funds and resources care remains an on-going debate, however it would seem that access to hospice services for frail older people is shaped by the 'choice offer' (National Palliative and End of Life Partnership, 2015) of service availability rather than simply professional, individual or family wishes. This would reiterate the study findings that referral decisions are in part 'managed' by staff within a context of service availability, rather than simply patient and carer choice.

### **8.5.2 Perceptions of need and BAME groups**

Normative or professional perceptions of need may influence the referral of particular groups. Despite efforts, the study was unable to recruit participants from BAME groups, possibly reflecting general UK trends in low BAME usage of hospice services (Calanzani et al. 2013). However, it was clear that referring staff from within the community team, and local oncology unit perceived family as central to the provision of care for BAME groups, and that BAME preferences for family care accounted for the lack of hospice use. Two Managers however, did question whether such assumptions were justified. Indeed, work by Cowan (2014) and Venkatasula (2013, 2011) suggest that intergenerational shifts are altering family patterns of care, and ethnocentric perceptions of need may be out of kilter with current demographic trends. It is also possible that hospice services are unfamiliar to those from BAME groups, as Gysels (2015) argues that a lack of international exposure may influence the understandings of those from a non-UK background around what hospice care is and what it can offer (given that hospice care has emerged predominantly within UK settings). Finally, it is unclear whether services that focus on an individualistic model of choice and decision-making are culturally desirable for those from a different cultural and religious background. Whilst there is a lack of a BAME perspective in this study, observations by staff suggest that it is possible that assumptions by both BAME groups and service providers could be denying BAME groups access to care. Such observations reflect current policy concerns (for example, Quality Care Commission 2016, Calanzani et al. (2013)

and Dixon et al. (2015)), and the study site recently appointed a community engagement officer to explore issues of access.

### **8.5.3 Ambivalence in recording patient needs and planning care**

Staff were ambivalent regarding bureaucratic approaches to managing 'the patient journey', and the requirement to complete certain documentation around care preferences and DNACPR orders. The early work of Seale (1998) asserts that death planning (documenting care wishes) presents as a 'good death' in enabling staff to manage death. Staff in this study occupied a juxtaposition between two distinct approaches to care. The reluctance of staff in this study to engage fully in templates for decision-making suggests staff implicitly acknowledge the challenge for individuals experiencing an uncertain and transient state in making decisions around future unknown care needs. However, whilst palliative care has its foundations in holistic care (Saunders 2000), James & Field's (1992) work identifies an organisational shift toward a more bureaucratic and metric driven model of care akin to that of mainstream care. Indeed, Borgstrom (2015) and Borgstrom & Walter (2015) argue that issues of service availability, cost effectiveness and containment have led to a focus on quality and outcomes, resulting in tendency toward a 'standardised approach' to care which omits to acknowledge the relational and complex negotiations of care and choice at end of life. Broom et al. (2015) cites similar challenges within the nursing role in the Australian context, in which nurses attempt to support patients at a personal level, whilst at the same time having to meet complex organisational and interprofessional demands. Cobb's work (2001) also captures the disjuncture between compassion and bureaucracy asserting that professionals and organisations overlook the more nebulous existential and spiritual aspects of palliative care in the need to focus on efficiencies and costs. This can cause discord, for as Cobb (2001, p.129) writes, professional carers 'have deeply human relationships with those they care for'. Clarke (2005 p.30) suggests that tools are in some ways maps which serve to control, appropriate and constrain the social world. Funk et al. (2014) similarly suggests that emotional labour within palliative care requires meaning making. The journey metaphor may therefore serve to provide staff with a means of conceptualising their role and managing their ambivalence in

supporting families and patients, whilst also prescriptively documenting decisions and completing proformas.

One of the challenges for staff was how to assess and document patient wishes and needs in relation to future care. There was however some scepticism regarding documentation generally with ambivalence around the timing and efficacy of documentation. Partly this may reflect staff preference for intuition when supporting patients, or scepticism around the ability to communicate effectively across teams. The SPARC tool (Ahmed 2015) offers a potential means of identifying patient needs and signposting support required, and some staff identified this tool as a positive intervention. Other staff participants were less positive, given that the tool offered a 'snap shot' in time, and failed to capture shifts in care needs, awareness or preference, which were also challenging to communicate across different health teams. Opportunities to review decisions were limited; raising some concerns given work by Wood & Salter (2013) that people's priorities can change over time. Some scepticism may also reflect the work of Charalambous & Goldbert (2016) in that nursing documentation is prone to omissions, duplication, and inconsistency. However, the introduction of the Electronic Palliative Care Coordinator Systems (Public Health England 2014) recording system has the potential to address issues of communication around patient needs and preferences. A recent toolkit however, focussing on service commissioning (NHS England, 2016) presents the innovation as an information-gathering tool to aid commissioning rather than a decision-making tool for staff and patients. Nevertheless, evaluation is anticipated and may prove positive.

Other models around decision-making and readiness to discuss care exists within palliative care literature, including Knight and Emanuel's reintegration model (2007) and Spranger & Schwartz (1999) theory of response shifts. These offer a template for recognising stages of transition rather than an intervention or tool with which to measure transition and readiness to engage in decision-making. Identifying patient and carer readiness to engage in choice

and decisions using metrics therefore remains elusive, whilst opportunities to review remain limited.

#### **8.5.4 Patient perceptions of need and ‘journey’**

The sense of sanctuary or refuge that patients expressed suggests that the hospice offered not ‘just a day out’, but an escape from social isolation. At the same time patients experienced discharge as uncertain and unknown, adding a sense of insecurity. Such experiences suggest that there was a lack of clarity between patient, carer and staff understandings of need and the purpose of the therapy unit. Patients were initially reluctant to attend but were encouraged by staff, who often emphasised the physical aspects of care as a means of ‘getting people through the door’, whilst short-term attendance was presented as an inducement to attend. The focus on physical aspects of care may reflect the assertion by Walter (1994, p.59) that ‘the journey’ of the good death is often expressed as one of personal growth, autonomy, and informed choice, “whilst the most heinous sins are social isolation and psychological denial”. Despite the emphasis on physical care, in reality, however, there was tacit recognition by staff and patients that psychosocial needs were significant. Bradley (2011) identifies similar findings in a study on hospice day care, which suggests that patients valued hospice day care as a psychosocial intervention, and reflects earlier work by Fisher et al. (2008), Edwards (2005) and O’Connor (2008) that present hospice day care as a therapeutic space to reflect. Hospice can therefore provide a temporal space for patients to adjust to a terminal status and reaffirm self-identity.

Discord between staff and patient perceptions reflects De Vries’s (2012) study in which staff believed that attendance created patient dependency; meanwhile patients felt that they deteriorated without the psychosocial support of the hospice. A similar dynamic was apparent in the current study and patients expressed dismay when faced with discharge and a return to coping alone. Meanwhile the positioning of carers outside of the service caused them uncertainty around the function of the hospice and their role. The fact that

patients and carers were not involved in discharge decisions also suggests that whilst staff purported to 'being there', there was a more persuasive element to their role in supporting transition.

A patient focus on coping with the everyday presents a further example of dissonance between staff and patient perceptions of needs and transition. Patients were very involved in meeting everyday needs including financial issues such as statutory benefits, work assessment, pensions and employment rights, and supporting others. Two had worked hard to negotiate care packages, indicating that exercising choice was onerous but a necessity in order to manage daily living. Similar concerns are prevalent in current debates around health and social care including the Kings Fund '*A new settlement for health and social care: final report*'(2014), and the Dilnot Commission (2011) which highlight inequities and challenges for service users in negotiating and funding care packages. Interestingly, staff interviews, did not allude to the often onerous and stressful everyday concerns of patient (although it is recognised that the inclusion of social workers in the study may have added further insights), and yet it is likely that pressing every day concerns reduce patient and carer capacity for exercising choice around future care decisions.

Transition to a terminal status also involved a patient focus on supporting others, including older relatives or offspring. It was striking that of the fifteen patients interviewed; twelve had a caring role and were actively involved in supporting those around them. Where there was discussion of future care options, this tended toward an altruistic and necessary wish to support and provide for others. The study findings are consistent with those of Hospice UK (Payne & Morbey 2013), which identifies that within the context of longer lives and multiple roles, patients are more likely to occupy a dual role of both carer and patient. The experiences of patients in this study suggest that 'becoming terminal' is not a complete biographical disjuncture but is adaptive, in that whilst some were relinquishing responsibilities, their role as mother, sibling, son or daughter nevertheless continued. Similar findings by MacArtney (2016) indicate that although hospice care is initially resisted, relational concerns around burden and support for carers shift preference for place of care. In the current

study, staff tended to focus more on individualised patient centred care rather than the need to support patients *and* their carers. The impact of relationships and social networks on patient choice and decision-making has the potential to be overlooked by staff in the context of person centred care. Borgstrom (2015), Broome (2012), Broom & Kirby (2013) and Kirby et al. (2014) cite similar findings in that decisions often reflect a network of relationships and responsibilities rather than simply the wishes of an autonomous individual.

### **8.5.5 Carer perception of need and journey**

Staff appeared to focus predominantly on patient needs rather than those of carers. As a result carers tended to occupy a positioning outside of the 'patient journey', in which the hospice was the 'end of the line', often following many years of caring. The positioning of carers as being on the outside reflects the findings of Payne & Morbey (2013) in that professionals often overlooked carers' needs and only rarely involved carers in care decisions. Staff in this study whilst positioning carers as outside of person centred care, did however recognise carers as needing support. This predominantly took the form of encouraging carers to take time out from caring, and the hospice provided a regular carers support group, (although it was poorly attended).

Encouragement to 'take time out' and relinquish care contrasted acutely against the highly vigilant role adopted by carers and therefore it is possible the support group did not meet carers needs, hence the lack of engagement.

Aoun et al. (2015) argue that an assessment of carers needs looks toward a model of care which recognises carers' needs but also carers' expertise. Working jointly with families and patients, rather than an individualised approach to care, may conflict with a person centred care approach advocated in current policy documents, for example, '*What's important to me*' (Choice in End of Life Programme Board, 2015). However, an approach to care which focuses on relational decision-making (as advocated by Borgstrom & Walter 2015, Wilson et al. 2013, Broome 2012 and Broom 2015) rather than an individualised model of autonomy might go some way to reducing the distress of

carers. To separate individuals from their support system or their caring role would seem to contradict the drive toward home care, choice and resilience advocated by a number of policy groups including the Leadership Alliance for the Care of Dying People (2014).

## **8.6 Domain 2: Health literacy in facilitating or inhibiting transition.**

The second element of domain two around facilitators and inhibitors explores the role of health literacy in shaping transition. There is growing public health movement within palliative care which advocates that all individuals have an awareness of death and dying in order to exercise agency around their dying choices (Kellehear 2013). Knowing what services are and what they provide is a prerequisite for choice and decision-making. Such an awareness requires a level of health literacy. Nutbeam (2000) provides a typology of health literacy using three levels including: firstly, a basic health literacy; secondly, the ability to process and interact with services to manage everyday health concerns, and thirdly, a critical health literacy that focuses on choice, empowerment and increasing autonomy. Understandings by staff, patients and carers around services suggest that health literacy at levels two and three would appear to be lacking with regard to accessing hospice care and planning future care.

Despite recommendations for earlier conversations around choice and palliative care (Morris, 2012 and the National Council for Palliative Care, 2016), this study indicated mixed understandings by carers, patients and staff, around palliative care and advance care planning. Similar findings are evident in a number of studies around public awareness and palliative care. For example, work by Clarke & Seymour (2010) revealed mixed understandings around advance care planning amongst older people, and later work by McIlpatrick et al. (2014) identified that public understandings of palliative care were generally unclear unless individuals had prior experience. Marsella (2009) in the Canadian context and the *'Fifth report of end of life care'* (House of Commons 2015) cites that even health professionals express some uncertainty around the

terminology employed within palliative and end of life care, resulting in calls for further end of life care training.

There are also issues around health literacy and interprofessional working. Patients in this study could not always identify who had referred them and when, nor who might support discussion around future care planning decisions. The staff interviews did not cite integrated working nor were communication processes around discussions and decisions clear. Warnock et al (2017) in the context of breaking bad news reflect that challenging conversations should occur at 'multiple moments' from diagnosis and beyond, and draw attention to interprofessional roles and staff responsibility as important considerations in how information is given and supported. Hannon et al. (2017) in the context of an oncology unit suggested that patients and carers received early involvement of palliative care approach (described as monthly visits, support and information) positively. Their work suggests that rather than an abrupt transition from curative to palliative services, a more integrated approach may provide a continuum of support rather than a disruptive transition.

The National Palliative End of Life Care Partnership (2015 *'Ambitions for Palliative and End of Life Care'*) remains committed to patient ownership of care decisions, and advocates the use of care coordinators who will navigate and communicate patient decisions using the electronic palliative care coordination systems (Public Health England 2014). The impact of such initiatives is currently unknown. Integrated care describes a system whereby care is coordinated, and encompasses a range of expertise including that of carers and patients, and takes into account the social systems that surround the patient and family and as such offers a means of ensuring continued dialogue. Hasselaar & Payne. (2016) in a review of integrated care across Europe argue that integrated care encompassing both health and social needs interlocks neatly with the early underpinning principles of holistic care within palliative care. However, given the discussion around potential models it would seem that such an approach is an evolving rather than an established practice. Hasselaar & Payne (2016) argue that integrated care should operate along four levels, including patient and family level, organisational level, regional level, and

national health system level. The principle of integrated care which reaches across generalist to palliative care systems and which centres around patient and carers would appear to address some of the issues found in this study, chiefly the uncertainty of transition, the need for continued dialogue and review of changing needs, and the involvement and support of patients and particularly carers.

Most of the patients, carers and some referring staff were aware of the hospice through either past personal experience of caring, visiting friends or family, or attending fundraising and publicity events, such as the festival of lights and various memorial events. However, in the interviews participants often referred to Macmillan cancer services rather than the hospice illustrating the association of hospices with terminal cancer. This finding is consistent with the work of Wood and Salter (2013) in which hospices were a 'misunderstood location' with only carers or patients with prior experiences fully considering hospice care as an option. Hannon et al. (2017) cites patient discomfort around the term 'palliative' and connotations of death. The increasing use of the term supportive care in health policy suggests that the term 'palliative' is perceived negatively, and possibly associated with euthanasia. Media furore over the Liverpool Care Pathway described popularly as a pathway to euthanasia (see for example, Philips 2012), has not helped to reduce negative and distrustful associations around palliative care and euthanasia.

There is currently a re-envisioning of hospice care along a number of themes, suggesting that palliative care is in itself in flux. For example, there is a shift toward encompassing a wider range of conditions, including dementia care (see for example, the Hospice UK (2015) report, '*Hospice enabled dementia care*') as well as remodelling hospice services along a community-orientated model of hospice care. There is also debate around further integration of specialist and generalist services (Seymour & Cassel (2016), and Wood and Salter (2013)). However, there is a danger that if current understandings of hospice services are unclear (Wood and Salter 2013), then future changes, particularly if diverse in the context of local commissioning following the Health & Social Care Act (2012), may further undermine health literacy and choice in the transition to

hospice services. Shifts toward earlier palliative care interventions offer a less disruptive transition; nevertheless, definitions of supportive and palliative care require clarity.

Being only partly NHS funded, hospices are independent and charity based services with the added role of fundraising. The hospice was concerned to raise public awareness and profile and a rebranding exercise occurred during the course of the study. The branding or marketing of hospice care potentially shapes how people understand services and care. Hospice UK has engaged in a number of initiatives to challenge negative perceptions of hospices including the 2016 media campaign '#notdingy'. Whilst this campaign has challenged 'dingy' media presentations of hospices, the alternative images present hospices as cleansed of death and dying (Borgstrom 2016). This presents a conundrum as on the one hand such measures aim to dispel the negative image of hospice care but at the same time underplay the hospice role in death and dying.

## **8.7 Domain 3: Patterns of response**

The following section explores the third domain within Meleis' et al. (2000) transition model regarding patterns of response. The experience of patients and carers in this study suggests that transition was disruptive but also transient. Gardiner et al. (2011b) discuss transience as a concept in palliative care citing the work of Larkin et al. (2007) which captures that rather than a shift toward resolution, transition in palliative care is uncertain, disorientating and full of presentiment. Larkin et al. (2007) describes transience as a nebulous concept but one that has increasing significance in palliative care. Whilst the model outlined in Figure 18 (see section 8.3) suggests that patterns of response should capture issues of mastery and completeness, the nature of 'the journey' in this study is uncertain and disruptive with death as a destination. Whether mastery or acceptance is achievable or desirable in the context of dying is debatable. Nevertheless, the findings suggest that patient, carers and staff attempted to respond to the uncertainty of transition.

Patients and carers focused on the certainties of death, such as funeral planning, and legacies whilst at the same time trying to manage everyday living. This in many ways reflects that people with palliative care needs are often living (and dying) for many years (Meier 2017). Managing the certainties of dying reflects not a denial of death nor an absence of choice but suggests that planning a funeral and legacy offered a sense of control, contrasting against the less predictable uncertainties of dying. There is also a remoteness to funeral planning that is perhaps easier to contemplate and more familiar than the impending uncertainty of dying. The focus on funerals rather than care planning also resonates with Carel's (2016) work from a phenomenological perspective, in that for those facing death, the transition is less about dying and more about 'being towards death'. Similar findings are also evident in the work of MacArtney et al. (2015b) in which dying whilst living is a 'parrelax' experience of liminality that oscillates between different realities of living and dying. Rather than a linear transition, MacArtney et al (2015b) assert that patients look for control and certainty as they move between the spheres of living and dying. The current study reflects similar dynamics in which patients were not in denial but oscillated between hospice and acute care and everyday living (as well as moving between carer and patient).

Franks (1995) identifies three narratives around illness and biographical disruption, including restitution (an attempt to rewrite a survival narrative), chaos (in which control of one's narrative is lost) and quest (to search for a new narrative). A focus on the everyday, may present as a means of quest or restitution in retaining a sense of self in the face of uncertainty and Gott et al. (2008) report similar responses in the context of heart failure. Taking each day at a time provided the means to manage living whilst dying and created a sense of normalcy. Similar dynamics were present in the current study and Etkind et al. (2017) argue that coping with uncertainty is a key experience of serious and life threatening illness, and that professional acknowledgment of uncertainty is important in understanding and supporting patient responses.

Carer response to transition was that of distress, particularly in not knowing how to ask for information and lack of involvement with care decisions. There was a positioning of carers as being on the outside, and staff regarded those who persisted in a coordinating role with unease as though deviant. For some of the carers (and patients) the key hospice contact was with volunteer drivers reflecting recent work by Jors et al. (2017) that often nonprofessional staff work hard to provide support and 'tend hearts'. Such experiences reflect the work of James et al. (2009), which found that professionals kept carers at a distance. This positioning reinforces carers as an entity to be 'managed' by staff.

Carer involvement is also challenging for staff who have a responsibility to support person centred care and confidentiality. There was also a potentially benign intention to provide time out for carers. Indeed originally, hospice day centres aimed to support patients but also provide a form of respite for carers (see Chapter two, Noble & Winslow (2015)). However, the encouragement to take time out contrasted against their highly vigilant caring role and reinforced a sense of presentiment that transition to the hospice was the end of the line. Carduff et al (2013) identify similar findings in study exploring primary care experiences and identified that both staff and carers were ambivalent regarding carer support. Broom & Kirby (2013) and Kirby et al. (2014) report similar dynamics within the Australian context, and identify the construction of carers by professionals in the context of palliative care referral as both a resource and obstacle. With the current emphasis on home care in palliative care (and by default provision of care by carers), there is a need to reconsider how carers are supported and involved in care.

Staff responses to transition were captured in the sense of 'being there' and with an emphasis on intuition and trust building. Whilst 'being there' implied a passive role for staff, the efforts to 'get people through the door' reflected a persuasive approach resonating with the observations of Eschenbruch (2007) in which hospice staff used 'employment' or 'meaning making' to encourage acceptance of interventions that nursing staff felt would be beneficial. Staff use employment to encourage engagement in order to achieve a positive outcome (as perceived by staff), for example, believing that persuading a patient to sit in

communal area may help to interact socially and lift mood. 'Emplotment' is a term originally coined by Mattingly (1994) and describes creating a narrative around a therapeutic intervention in which patients are encouraged to engage in a story or plot which 'may turn out' differently than they anticipate. This may present as a benign and compassionate approach to supporting patients at a critical transition point, however, this approach also underplays the role that staff exercise in 'managing' and even possibly manipulating transition. There is also a lack of transparency and openness, raising questions around who is offered choice, which choices are offered and how.

Transition from a stage of uncertainty to one of acceptance fits with the script of the 'good death'. Engaging in advance planning and access to hospice care also captures notions of individual responsabilization (Brown & Baker 2013) in managing one's own death; however, participants in this study were ambivalent around care decisions, on the one hand not knowing what care could and would be required but also recognition of uncertainty. The emphasis on an individual or a person centred journey overlooks the experience of patients and carers for whom the journey is not linear but precarious and isolating. McIlfatrick (2007) notes similar experiences in that patients' and carers' concept of a journey was less linear and instead viewed as a continuous series of events.

Integrated care is advocated as best practice in supporting patient and families (Hasselaar & Payne 2016), alongside a focus on place of care. The recent "*Our commitment to you*" (DH 2016) requests that commissioning groups are clear about the 'efficiencies' to be made around advance care planning and avoidance of hospital admission. Such admonishments suggest that the concept of the patient journey is in part a form of governmentality described by Miller & Rose (2008) and Rose (1990) as means of shaping and managing personal conduct using the constructions of both expertise and 'the liberation of self' and autonomy. In this context choice presents as a double-edged sword in that notions of choice and freedom 'obliges' an 'ethic of autonomy' (Murtagh (2009, p. 82). The staff construction of a patient journey in some ways presents as a pragmatic response to what Pollock & Wilson (2015) in the context of advance care planning eloquently articulate as a 'disaggregation' of competing

priorities around autonomy, notions of the good death and emphasis on quality and cost effectiveness. Such disaggregation suggests that integration of care delivery within palliative care and across palliative and generalist services faces a number of challenges.

## **8.8 Summary of discussion**

This discussion chapter has explored the core category of transition and transience in unpacking choice and decision-making in how people accessed a hospice day unit and reflected on future care choices. The experiences of staff, patients and carers suggest that opportunities to engage in a rational decision-making process were confounded by a disruptive and emotional transition. In this study, patients, staff and carers did not appear to engage in a process of shared decision-making. Instead, decisions around care were constrained by staff, patient and carer perceptions of need, and ultimately the uncertainty and transient nature of dying.

Staff conceptualised transition as a 'journey' in which staff intuitively supported individuals and carers. However, in practice a mix of bureaucratic, organisational, professional and interpersonal tensions shaped professional perceptions of need, resulting in a 'managed' response to choice and future care planning. In contrast, patients focused primarily on managing everyday living, particularly care packages and social isolation, along with the need to support others. At the same time, uncertainty around death and dying and perceived lack of choice undermined active engagement with choice around referral and future care planning. The patient focus on others suggested relational aspects of care were a priority. However, carers were positioned outside of care decisions, and needs were shaped by a sense of presentiment and loss. Issues of health literacy underpinned understandings of palliative care and influenced referral and future care planning decisions.

Prior experience influenced understandings of hospice care. However, health literacy, awareness of services and engagement in decision-making was limited in all three perspectives. The findings illustrated mixed understandings of hospice care with evident confusion around terminology, particularly with regard

to future care planning tools. The emphasis on home care and on-going debates around generalist versus specialist care suggest that palliative care is in flux, which may further obfuscate understandings.

Notions of informed choice tended to be normative and professionally constructed within a context of cost efficiencies and limited resources, with home and hospice care presented as more desirable than hospital care. Further work is also required to explore patterns of inequalities particularly around perceptions of need and service models in order to ensure culturally sensitive care, equity, and equality of access for all.

Situating the discussion within existing models of transition provides an abductive approach to exploring access to a hospice day unit. The Meleis et al. (2002) model of transition provided a framework within which to explore patients, carers and staff experiences. The model was constructive in illustrating: firstly, that perception of needs and health literacy shaped the condition and nature of transition to hospice services; secondly, that it was experienced as disruptive; and thirdly, that the 'patient journey' encompassed a number of critical and transient transition points. However, a sense of presentiment and uncertainty was evident in all accounts. Responses by patients emphasised a focus on managing the certainties of dying, as well as a focus on the everyday. Staff responded with a focus on 'being there' conceptualised as managing the patient journey which required a balance between organisational and interpersonal constraints to care. Meanwhile, carers responded as vigilant outsiders 'wondering how long'.

The data suggest that individuals experience dying as transient, and uncertain. A combination of living in the everyday, particularly supporting others, and planning the certainties of death (including legacy) provided a means of coping with uncertainty but was also necessary in order to manage the practicalities of death and dying. Anticipating future care needs was challenging for patients, carers and staff as these are often unknown, and unclear, and in contradiction to current palliative care policy in which advance care planning presents as a key outcome. The fourth domain of the transition model will focus on nursing

therapeutics and will provide the basis for recommendations for policy and practice in the following concluding chapter.

# Chapter 9: Conclusion

## 9.1 Introduction

This concluding chapter will provide an overview and summary of the study exploring how people come to use hospice services and staff, patients and carers negotiate choice and decisions. This will include a consideration of the strengths and limitations of the study, using Charmaz's (2006) criteria of credibility, originality resonance and usefulness. Finally, the study will explore the theoretical concept of transition and transience in palliative care with implications for practice.

## 9.2 Strength and limitations

Charmaz (2006, 2014) outlines four criteria for evaluating SCGT including credibility (familiarity with setting and topic, constant comparison and iterative exploration of categories); originality (does the work offer fresh insights); resonance (whether the findings make sense to participants, and provides insights into their life world) and usefulness (what are the implications and contribution to knowledge).

### 9.2.1 Credibility

This study adopted a constructivist grounded theory approach to explore how people came to use hospice services. As with all qualitative approaches, there is a focus on interpretation and justification of claims (Denzin & Lincoln 2000). Charmaz (2006) suggests that reflexivity offers a means of transparency around how data are explored and interrogated. This study spanned a period from 2010 to 2017 occupying a number of transitions within my own life. It is not always clear to ourselves how we may understand another viewpoint, but it is likely that those aspects, which resonate with our own, lead us to project our own feelings, emotions and judgements on to others but may also lead to us to be cognizant of understandings that an outsider may not. Chapter four, 'Methodologies and Methods' documents how analysis aimed to explore 'taken for grantedness' as well as surprise or difference within the interviews. For

example, a deeper exploration of the 'patient journey' analogy enabled a consideration of the implications of this term on processes and actions.

Charmaz (2006) advises consideration of sufficiency of data as part of credibility. Full theoretical saturation may be an endless quest (Flick 2014, p. 417) if it is accepted that constructivist approaches accept different interpretations. In this study, familiarity with the setting and topic was both personal and professional. Immersion in the data was a prerequisite in evidencing the core themes. This study acknowledges however, that data around frail older people and BAME groups was through secondary discussion rather than with representatives from these groups. Nevertheless, the interviews were insightful in gathering the perspectives of staff around access to services for older people and those from BAME groups.

Work by Funk (2009) asserts that longer sustained relationships with participants enable fuller understandings of responses to end of life care. However, the nature of time within the context of palliative care and resources of a doctoral student precluded continued and long-term contact. Nevertheless, data collection occurred over a two-year period and contacts with staff and patients enabled a deeper contextualisation of data than one-off snapshot interviews.

### **9.2.2 Originality**

This study illustrates that access to hospice care is a transitional process with multiple and transient transition points, within a highly emotional context. The overarching theme of transition and transience captures this complexity. This study utilises Meleis et al's (2000) transitions framework in which transition presents as predominantly linear and with a final stage of acceptance. Such an approach would concur with constructions of the 'good death', particularly around an open awareness and acceptance of dying. However, this work presents a challenge to Meleis et al.'s transition framework in that the transient nature of dying challenges the construction of the good death in which the 'responsibilized' individual engages in the planning of their care. Transition is

not linear but has multiple transition points in which a focus on advance care planning fails to acknowledge the uncertainties of dying. The concept of the 'patient journey' serves to present a coherence to how staff support patient and carers however, the reality is more 'managed' and yet incoherent given the opposing forces of quality, cost effectiveness, and the challenges of advance planning for what is often uncertain and shifting. As such, patient and carer engagement in a shared decision-making process is questionable in terms of desirability and achievability. Reconceptualising the journey within an integrated approach to care could provide a more ongoing dialogue around choice and needs in addressing the priorities of patients and carers.

### **9.2.3 Resonance**

I employed theoretical sampling test ideas around coding and categories within the interviews. The initial patient interviews, and interviews with staff and carers were explored before returning to interview a further four patients, thus allowing some early testing of core categories and exploration of categories within the interviews. The data analysis was iterative in comparing and contrasting staff, patient and carers data around 'the patient journey'. Deeper explorations of the significance of this metaphor led to further insights around transition and transience, within palliative care.

A pictorial approach also enabled participant opportunity for review and co construction of narratives. Finally, an early analysis presented to the hospice management team including managers and practitioners, indicated that issues around branding, access to services by BAME groups and carer support echoed with the concerns of the hospice team and resonated with recent reports from Hospice UK. Indeed, the hospice later recruited additional personnel with a remit to explore issues of access to services for BAME groups, and innovative ways of developing carer support. The hospice was also concerned with how to raise awareness around hospice care. As a result of the presentation and subsequent discussion I was asked to lead on facilitating a death café as a joint university and hospice initiative as part of Dying Matters Awareness Week (2014 and 2015) as a means of 'piloting' what was a relatively novel initiative with students.

### **9.2.4 Usefulness**

During the period of the study, a number of policy shifts were evident. These reflected specifically a focus on place of care as well as a growing public health focus and on-going debates around specialist versus generalist palliative care (Seymour and Cassel, 2017) continue. This would imply that palliative care is itself in flux. This study is therefore useful in contributing to the developing evidence base within palliative care practice around decision-making and two published outputs have contributed to this effect (Appendix 2, and 3), particularly around the need for an interpretation of autonomy which includes relational decision-making. Furthermore, the findings suggest that greater recognition of transience within the transition to palliative care, and a stronger focus on integrated care which focusses on patient and carer needs would help to support patient and carers facing end of life, rather than an uncritical approach to the 'patient journey'.

On a practical level, as an outcome of this study, the study site was keen to explore initiatives raising public awareness of hospice services. I was able to lead on a collaboration between the hospice and Sheffield Hallam University to explore the impact of a number of death café events on raising awareness. Health and social care students evaluated the events positively and findings were presented at the Sheffield Hallam Learning and Teaching conference 2015 (see Appendix 19) and as part of a Cancer & Palliative Care Showcase event in May 2016 (Sheffield Hallam University and Public Health Hub (see Appendix 20).

### **9.2.5 Further reflections on strengths and limitations**

The 'doing' of real world research within a palliative care setting led to a mix of purposive, theoretical and convenience sampling. The study aimed to include perspectives of those more marginalised including BAME groups as well as older frail people, and those with conditions other than cancer. The sample all self-identified as having cancer even where there was co morbidity. The demographics of the sample suggests that older people are not precluded from

accessing hospice services. However, interviews with referring staff suggest that access for frail older people is possibly constrained by resource implications and staff perception of need. Accessing those clinical areas in which referrals are likely to occur could have provided further insights into decisions around access to hospice care. Gender was a further dimension of the sample being predominantly female, and this would suggest a gender dynamic to choice and decision and suggests that future work specifically focussing around this social determinant of health would be of value.

A wider diverse selection of the interprofessional team, including social workers and GPs, would have added further insight into care decisions and choice. Nevertheless, the study does present a range of perspectives, particularly including referring staff. However, I acknowledge that the writing up of the study took some time, and initiatives to develop integrated working are already in practice. For example, the hospice is currently pioneering the EnComPass project, a technological innovation combining the Integrated Palliative care Outcome Scores (IPOS) to enable an integrated care team response to patients and families at home and to aid communication between staff, patients and carers. The development of an additional hospice location has also increased the potential to support care to carers and people with a life limiting illness. Such innovations may prove positive and evaluation will be insightful regarding the impact on care and choice in palliative care.

### **9.3 Domain 4: Implications of ‘Transition and Transience’**

This following section provides a summary of the overarching core category ‘transition and transience’ and will conclude with an exploration of the fourth domain of Meleis et al’s (2000) transition model; ‘nursing therapeutics’. This domain enables an exploration of the implications for practice, policy and future research.

This study emphasises transience as a key feature in the transition to hospice care. As such, the findings contradict a transition framework that assumes transitions are linear, and which conclude in a final stage of acceptance and

personal growth. For patients and carers in this study, the move toward hospice care and the ambivalence around future care planning reflected a disruptive and emotional experience in which the opportunity or desirability for engagement in future care planning was challenging, and reflected the uncertainty and presentiment inherent within dying and ultimately death.

The journey metaphor visible within accounts presents as a salient analogy given the history of hospice care as a place of pilgrimage and the emphasis on pathways within person centred care. However, a constructivist approach permits the unpacking of everyday language and taken for granted concepts, enabling an examination of language for action and process. Charmaz (2006) argues that asking what would happen without articulation of a particular term or phrase term can reveal meanings and process. The journey metaphor paradoxically helps to articulate the experience of transition from diagnosis to hospice referral as the acquisition of a terminal status, but also serves to mask the temporal uncertainty of the transient nature of dying.

Staff occupy a difficult position in both delivering emotional support for what is uncertain whilst also meeting organisational and professional needs. The journey is both a form of governmentality and management of self (Miller & Rose 2008) presenting a particular view of choice (chiefly place of care/death), and yet serves to provide a humanistic response to care. An intuitive approach to the journey in 'being there' serves to conceptualise that patients are supported. However, the journey is also 'managed' through a process of tentative interaction and subjective assessment of need. Discharge plans were uncertain for patients and carers, suggesting that decisions around care and services are not a shared negotiation, but informed by staff and service availability. Anticipating future care needs was challenging for patients, carers and staff as these are unpredictable (and in some ways unthinkable) and provides a contradiction to current palliative care policy in which advance care planning is a means of supporting individualised care and a metric for quality.

For carers the hospice presents the end of the journey rather than the beginning, and is not only a place to die but also a challenge to their role as coordinators of care. The carer distress, grief and isolation within interviews

contributed to a sense of being on the outside or left behind. Such responses are highly emotional and painful, and suggest a relational rather than individualised person centred care approach would be of benefit to patients and those around them. A relational perspective to decisions and autonomy would support current palliative care policy in which home care and by default, family carers, are increasingly central to end of life care delivery.

### **9.3.1 Summary of key findings**

- Patient and carer decisions to access the day hospice was complex but generally resisted by patients. Trust in referring staff, crisis, and prior expectations or experience all influenced acceptance of referral.
- The analogy of a journey serves to conceptualise a linear process of transition to hospice care, however the shift toward death and dying is transient, and fluctuating rather than a linear shift from one phase to another. Furthermore, starting and endpoints may differ according to each perspective.
- Issues of choice are constrained by professional perceptions of need, resource implications, and quality metrics.
- Staff use the analogy of the patient journey as a temporal process of 'being there' and appear to adopt an intuitive and non-directive approach to supporting patients. In reality however, professionals implicitly 'managed' the journey as they balanced the demands of resource management, audit and quality, and organisational systems.
- The tentative and intuitive approach adopted by staff reflected an implicit acknowledgement that rational decision-making in the face of an existential threat was challenging given the human dimension of dying.
- A focus on the everyday rather than future care was important for patients, requiring energy, and negotiation in planning finances, and supporting others. This may be a denial of the unpredictability of

illness and dying, however, the demands of everyday living were pressing and onerous.

- Carers expressed a sense of exclusion, coupled with a level of uncertainty and anxiety that undermined their highly vigilant role and added to distress around the future.

The findings make an important and novel contribution to the debates around shared decision-making and advance care planning when facing end of life in the following ways:

- There was no clear route to how people access hospice services and despite the emphasis on choice and autonomy within current health policy;
- Prior experience, along with staff, carer and patient perceptions of needs shaped how people accessed the hospice day centre and expectations were underpinned by mixed perceptions of palliative care and hospice care;
- Given the temporal nature of death and dying as uncertain there are questions around whether decision-making is desirable or possible when facing end of life;
- Greater awareness and health literacy, for staff and services users and commissioners, along with earlier palliative care interventions are required to make autonomy and choice in using hospice services a reality. However, a blanket edict that focuses all individuals plan care in advance may be helpful for some patients and carers but insensitive to others;
- Given the impact of biographical disruption, response shifts and the temporal and transient nature of end of life, dialogue around care needs should be ongoing and with a transparency around services and purpose;
- There is a need to consider at what point decision-making around end of life care is appropriate, and how to support ongoing dialogue.

### **9.3.2 Implications for practice**

Resilience in living and dying for both carers and patients is important for supporting quality of life, and this is particularly salient given that most people are living longer with a terminal illness. Models of practice should aim to enhance resilience as well as the transient nature of transition to palliative care and should consider:

- Strategies to address psychological distress and social isolation in order to avert a crisis response to care and decisions;
- A focus on integrated interprofessional care that reaches within and across palliative and generalist care and which engages in ongoing dialogue around care may provide a supportive care model;
- The potential to reduce carer distress and utilise carer expertise through cooperative and supportive engagement between health professionals and carers. This is particularly salient given that some patients are also carers and vice versa;
- Care that focuses on how to cope with living in the everyday, rather than future care needs, including managing finances and planning for others.
- Relational approaches to decision-making and choice that encourage an ongoing, rather than 'snapshot' dialogue throughout the illness trajectory;
- How understandings of hospice services influence access to services and choice;
- Strategies such as outreach work to ensure that referring health professionals are familiar with hospice and palliative care services in order to facilitate access to services and choice.

### **9.3.3 Implications for policy**

The following considers the study findings within the context of increasing palliative care needs and limited resources and recommends:

- Further exploration of ‘compassionate communities’ in supporting individuals within a relational model is required to avert issues of social isolation and crisis for those facing end of life;
- Greater awareness of hospice services and palliative care as advocated within a public health model to stimulate further debate around service provision;
- Exploration of models of integrated care across all services including palliative care offers the potential to support patients and families in an ongoing process of care from diagnosis to death;
- Further consideration of public health initiatives, which promote awareness of death and dying such as Dying Matters;
- An emphasis on hospice outreach work to widen understandings and access, rather than focus on charity income;
- A continued focus on issues of equality and access, particularly regarding BAME groups, older people and gender;
- Palliative care for older people with co-morbidities should be reconsidered to ensure that wherever care is provided it is equitable and of quality.

### **9.3.4 Recommendations for future research**

Further research is required in order to develop and evidence practice and policy. The following suggests further research directions as follows:

- An evaluation of public health initiatives and debate around what palliative care is or could be, would contribute to issues of equity, equality and transparency around commissioning and purpose of services;
- Patterns of inequalities remain unexplored particularly around BAME groups and gender, requiring further work to explore perceptions of need and service models in order to ensure culturally sensitive care and access to hospice and palliative care services;

- The role of hospice and palliative care in supporting long-term conditions other than cancer is of growing interest given predicted increases in longevity and rise in co morbidities;
- Finally, future research into models of shared decision-making within the context of palliative care would be of value in informing how best to support transition to palliative care.

## 9.4 Conclusion

This study explores how people come to use hospice services. The findings illustrate that the transition from living to dying is uncertain and transient. Engaging in decisions around care including accessing hospice services is therefore challenging, fluid and shaped by relational considerations. Dying is not a passive transition but requires effortful and active engagement in supporting others, whilst also managing the liminality of everyday living whilst dying. The disruptive and emotional transition to hospice care challenges notions of choice, decision-making capacity, resulting in a 'managed' approach to care decisions. Health professionals capture the balance between 'managing' and 'supporting', in the analogy of a 'patient journey', suggesting elements of both governmentality and caring.

General factors shaping access to hospice services and care decisions include health professional, patient and carer perceptions of need, periods of crises, and prior knowledge. Acknowledging the uncertainty of dying whilst supporting individuals to manage everyday life, as well as an emphasis on relational care would help to meet patient and carer needs. Greater transparency, integration and awareness of services could facilitate transition and agency

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**Using social constructivist grounded theory to explore how people come to use hospice day care services: a theory of transience and transition**

**F M Wilson**

**October 2017**

**Volume II  
APPENDICES**



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**Using social constructivist grounded theory to explore how people come to use hospice day care services: a theory of transience and transition**

Fiona M Wilson

A thesis submitted for the partial fulfilment of the requirements for the degree of  
Doctor of Philosophy

Faculty of Medicine  
School of Nursing & Midwifery  
October 2017

Volume II:  
Appendix.

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# Appendix 1: Permission to use published materials

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 School of Nursing and Midwifery  
 The University of Auckland  
 Room 108, 301, Grafton Road  
 Auckland 1010  
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 Email: c.ingleton@uakland.ac.nz

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**Appendix 2:** Wilson, F., et al. (2013).  
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## Perceived risks around choice and decision making at end-of-life: A literature review

F Wilson, M Gott and C Ingleton

*Palliat Med* 2013 27: 38 originally published online 12 October 2011

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# Appendix 4: Wilson, F, Ingleton, C.,Gott M., Gardiner, C. (2014) Perceived Risks in Decision-making. Poster Presentation. *Proceedings of the 10<sup>th</sup> Palliative Care Congress 2014. Harrogate*

## Understandings of risk around 'choice' in end-of-life care: a literature review.

**Authors:**  
 Fiona Wilson, Senior Lecturer, Faculty of Health & Wellbeing, Sheffield Hallam University  
 Professor Christine Ingleton, Professor of Palliative Care Nursing, School of Health & Health Services, University of Auckland, NZ  
 Professor George Gott, Professor Health Services, Faculty of Health & Health Sciences, University of Auckland, NZ  
 Dr Catherine Gardiner, Senior Lecturer, School of Nursing, Faculty of Health & Health Sciences, University of Auckland, NZ

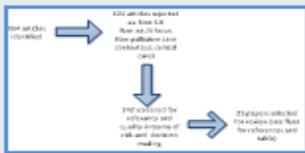
**Background:**  
 "A core value for palliative care has been to enable people to make choices about their end-of-life care and place of death". World Health Organization 2011  
 The term 'Patient choice' is present in all current health policy documents, including those focussing on palliative care. However it is not clear how 'choice' is understood or what risks are associated with particular choices.

"We want the principle of "shared decision-making" to become the norm: no decision about me without me." (DH 2010:13)

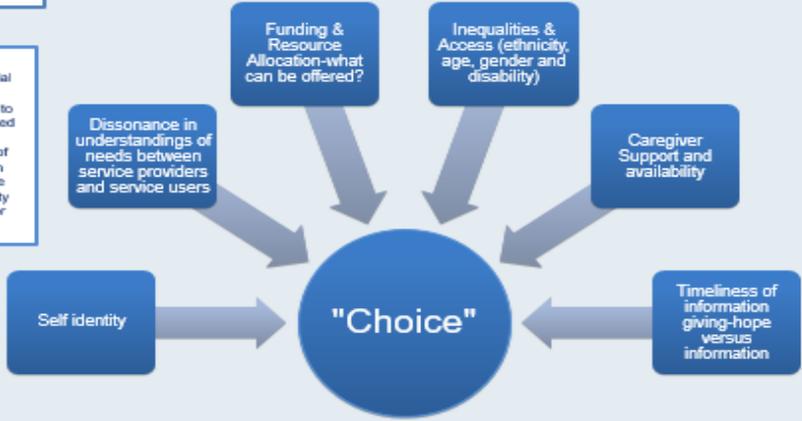


**Aim:**  
 An integrative literature review to capture understandings and risks around decision making in end-of-life care.

**Methods:**  
 Medline (Ebsco), PsCHINFO, Assia (Applied Social Sciences Index and Abstracts, British Nursing Index, High Wire Press, (CINAHL (Current Index to Nursing and Allied Health Literature) were explored using the terms "decision", "risk", "hospice and palliative care, end of life care". Hand searching of key texts also revealed relevant papers. Inclusion criteria included adult focus, 1998-2010 within the UK. 242 papers explored for relevance and quality (Hawker et al. 2002). 25 papers were explored for key themes.



### Findings: Key Themes



**Analysis:**  
 Autonomy of choice in decision making suggests a model of individual identity and independence. However "choice" in end-of-life care is defined by professional and service led understandings of service provision, resource availability and management of patient needs, whilst on an individual level, "choice" is based on social and cultural understandings and is constrained by vulnerability and availability of social support and services which shape interpretations of risk. Inequalities around age, gender, and ethnicity and class persist across the life course into palliative care. Ability to exercise choice and manage risks therefore depends on availability and understandings of what services can offer, information and information giving, and the narratives and experiences of the individual.

**Recommendations:**  
 Review of service provision around integration of care, cultural sensitivity and accessibility of services.  
 Recognition of complexity of decision-making using a model such as the decision ecology model (Broome, S et al (2012) which acknowledges the individual narratives around context, care and choice.  
 Exploration of care decision tools for holistic assessment of needs.

**Conclusion:**  
 Open not tacit, acknowledgement of understandings and constraints by key stakeholders including health professionals, and service providers may facilitate better understandings of decision-making processes in palliative care.



# Appendix 5: Hawker et al. (2002) Appraisal Protocol

## APPENDIX A Assessment Form 1: Reject/Accept

---

Author(s): \_\_\_\_\_ Date of Publication: \_\_\_\_\_  
 Abbreviated Title: \_\_\_\_\_  
 Reviewer: \_\_\_\_\_

---

**Relevance to Research Questions**  
 How effective are existing methods?  
 Is appropriate patient information provided on discharge?  
 What are the formal and informal strategies for transfer of information?  
 To what extent is information technology used?  
 What factors are associated with the breakdown of communication?

**Intracommunication (Hospital Community)**  
 Focus or major part of study  
 Minor part of study  
 Mentioned in discussion/results

**Intercommunication (Within Hospital)**  
 Focus or major part of study  
 Minor part of study  
 Mentioned in discussion/results

**Discharge**  
 To home  
 To residential care  
 Any documentation examined

**Source of Data**  
 Professionals  
 Elderly patients/clients  
 Carers/family

**Study Type: - (ring)**  
 [1] Empirical study—Peer reviewed  
 [2] Theoretical paper—Peer reviewed  
 [3] Research paper—Non-peer reviewed  
 [4] Theoretical paper—Non-peer reviewed  
 [5] Professional document  
 [6] Case study  
 [7] Other

**Comment:** \_\_\_\_\_

---

## APPENDIX D

1. Abstract and title: Did they provide a clear description of the study?	Good Fair Poor Very Poor	Structured abstract with full information and clear title. Abstract with most of the information. Inadequate abstract. No abstract.
2. Introduction and aims: Was there a good background and clear statement of the aims of the research?	Good Fair Poor Very Poor	Full but concise background to discussion/study containing up-to-date literature review and highlighting gaps in knowledge. Clear statement of aim AND objectives including research questions. Some background and literature review. Research questions outlined. Some background but no aim/objectives/questions, OR Aims/objectives but inadequate background. No mention of aims/objectives. No background or literature review.
3. Method and data: Is the method appropriate and clearly explained?	Good Fair Poor Very Poor	Method is appropriate and described clearly (e.g., questionnaires included). Clear details of the data collection and recording. Method appropriate, description could be better. Data described. Questionable whether method is appropriate. Method described inadequately. Little description of data. No mention of method, AND/OR Method inappropriate, AND/OR No details of data.
4. Sampling: Was the sampling strategy appropriate to address the aims?	Good Fair Poor Very Poor	Details (age/gender/race/context) of who was studied and how they were recruited. Why this group was targeted. The sample size was justified for the study. Response rates shown and explained. Sample size justified. Most information given, but some missing. Sampling mentioned but few descriptive details. No details of sample.
5. Data analysis: Was the description of the data analysis sufficiently rigorous?	Good Fair Poor Very Poor	Clear description of how analysis was done. Qualitative studies: Description of how themes derived/ respondent validation or triangulation. Quantitative studies: Reasons for tests selected hypothesis driven/ numbers add up/statistical significance discussed. Qualitative: Descriptive discussion of analysis. Quantitative. Minimal details about analysis. No discussion of analysis.

6. Ethics and bias: Have ethical issues been addressed, and what has necessary ethical approval gained? Has the relationship between researchers and participants been adequately considered?	Good Fair Poor Very Poor	Ethics: Where necessary issues of confidentiality, sensitivity, and consent were addressed. Bias: Researcher was reflexive and/or aware of own bias. Lip service was paid to above (i.e., these issues were acknowledged). Brief mention of issues. No mention of issues.
7. Results: Is there a clear statement of the findings?	Good Fair Poor Very Poor	Findings explicit, easy to understand, and in logical progression. Tables, if present, are explained in text. Results relate directly to aims. Sufficient data are presented to support findings. Findings mentioned but more explanation could be given. Data presented relate directly to results. Findings presented haphazardly, not explained, and do not progress logically from results. Findings not mentioned or do not relate to aims.
8. Transferability or generalizability: Are the findings of this study transferable (generalizable) to a wider population?	Good Fair Poor Very Poor	Context and setting of the study is described sufficiently to allow comparison with other contexts and settings, plus high score in Question 4 (sampling). Some context and setting described, but more needed to replicate or compare the study with others, PLUS fair score or higher in Question 4. Minimal description of context/setting. No description of context/setting.
9. Implications and usefulness: How important are these findings to policy and practice?	Good Fair Poor Very Poor	Contributes something new and/or different in terms of understanding/insight or perspective. Suggests ideas for further research. Suggests implications for policy and/or practice. Two of the above (state what is missing in comments). Only one of the above. None of the above.

## Appendix 6: Thematic Matrix

Author/Date/Title	Patient and carer perceptions of place of care	Caregiver Support	Funding and resources	Inequalities and inequity in accessing hospice services	Timeliness of information giving	Dissonance in service providers and patient and carers understandings of services
Addington-Hall J.M. & O' Callaghan (2009) Comparison of the quality of care provided to cancer patients in the UK in the last three months of life in in-patient hospices compared with hospitals, from the perspective of bereaved relatives: results from a survey using the VOICES questionnaire. <i>Palliative Medicine</i> 23(3) 190-197.		x				
Agnew et al. (2010) Bereavement needs assessment in specialist palliative care: a review of the literature. <i>Palliative Medicine</i> 24(1) 46-59.		x				
Bradley, Frizelle & Johnson (2011). Patients' psychosocial experiences of attending Specialist Palliative Day Care: A systematic review. <i>Palliative medicine</i> 25(3) 210-228.						x
Broom et al. (2012) Specialists' experiences and perspectives on the timing of referral to palliative care: a qualitative study. <i>Journal Of Palliative Medicine</i> 15(11) 1248-1253					x	

Broom & Kirby (2013) The end of life and the family: hospice patients' views on dying as relational. <i>Sociology of Health &amp; Illness</i> 35(4) 499-513.		x				
Broom et al. (2015) Negotiating futility, managing emotions: nursing the transition to palliative care. <i>Qualitative Health Research</i> 25(3) 299-309.					x	
Campbell et al. (2010) Exploring differences in referrals to a hospice at home service in two socio-economically distinct areas of Manchester, UK. <i>Palliative Medicine</i> 24(4) 403-409.				x		
Carduff et al. (2016) Piloting a new approach in primary care to identify, assess and support carers of people with terminal illnesses: a feasibility study. <i>Bmc Family Practice</i> 17.		.x				
Cotterell (2008) Striving for independence: experiences and needs of service users with life limiting conditions. <i>Journal of advanced nursing</i> 62(6) 665-673.	x					

Cowan (2014) The lived experiences of the Sikh population of southeast England when caring for a dying relative at home. <i>International Journal of Palliative Nursing</i> 20(4) 179-186.						x
Coupland 2011 Does place of death from cancer vary between ethnic groups in South East England? <i>Palliative Medicine</i> 25(4) 314-322.			x	x		
De Vries & Nowell (2011) Dementia deaths in hospice: a retrospective case note audit. <i>International Journal of Palliative Nursing</i> 17(12) 581-585.			x	x		
De Vries, Wells, & Plaskota (2012) Evaluation of an admission and discharge programme at a UK specialist palliative day hospice. <i>International journal of palliative nursing</i> 18(6) 275-281.						x
Dixon et al. (2015) <i>Equity in the provision of palliative care in the UK: review of evidence. Discussion Papers, 2894. London School of Economics and Political Science, Personal Social Services Research Unit, London, UK.</i>			x	x		

Enes et al. (2004) Discharging patients from hospice to nursing home: a retrospective case note review. <i>International journal of palliative nursing</i> 10(3) 124-130.			x			
Ewing & Grande (2013) Development of a Carer Support Needs Assessment Tool (CSNAT) for end-of-life care practice at home: A qualitative study. <i>Palliative Medicine</i> 27(3) 244-256.		x				
Eyre (2010) Supporting informal carers of dying patients: the district nurse's role. <i>Nursing Standard</i> 24(22) 43-46.					x	
Fergus et al. (2008) Is a STAS-based tool valid to triage patients at a specialist palliative care inpatient unit? <i>International journal of palliative nursing</i> 14(1) 24-29.			x			
Gage et al. (2015) Impact of a hospice rapid response service on preferred place of death, and costs. <i>BMC Palliat Care</i> (2015) 14: 75.	x					
Gardiner et al. (2011a) Exploring the transition from curative care to palliative care: a systematic review of the literature. <i>British Medical Journal of Supportive &amp; Palliative Care</i> 20(1) 56-63.			x			

Gardiner et al. (2011b) Exploring the transition from curative care to palliative care: a systematic review of the literature. <i>British Medical Journal of Supportive &amp; Palliative Care</i> 20(1) 56-63.					x	
Gardiner et al. (2014) Exploring the financial impact of caring for family members receiving palliative and end-of-life care: A systematic review of the literature. <i>Palliative medicine</i> 28(5) 375-390.						
Gott et al. (2004) Older people's views about home as a place of care at the end of life. <i>Palliative Medicine</i> 18(5) 460-467.	x	x				
Gott et al. (2008) At odds with the End of Life Care Strategy. <i>Nursing Older People</i> 20(7) 24-27.				x		
Grande et al. (2009) Supporting lay carers in end of life care: current gaps and future priorities. <i>Palliative Medicine</i> 23(4) 339-344.		x				

Harrop Byrne & Nelson (2014) "It's alright to ask for help": findings from a qualitative study exploring the information and support needs of family carers at the end of life. <i>BMC, Palliative Care</i> 13.		x				
Hunt et al. (2014) End-of-Life Care and Preferences for Place of Death among the Oldest Old: Results of a Population-Based Survey Using VOICES-Short Form. <i>Journal of Palliative Medicine</i> 17(2) 176-182.	x	x				
Kennedy et al. (2009) Key stakeholders' experiences and views of the NHS End of Life Care Programme: findings from a national evaluation. <i>Palliative medicine</i> 23(4) 283-294.			x			
Kessler et al. (2005) Social class and access to specialist palliative care services. <i>Palliative medicine</i> 19(2) 105-110.				x		
Kirby et al. 2014a Medical specialists' motivations for referral to specialist palliative care: a qualitative study. <i>BMJ Supportive &amp; Palliative Care</i> 4(3) 277-284		x				
Kirby et al. 2014b Families and the transition to specialist palliative care. <i>Mortality</i> 19(4) 323-341.		x				

for the <i>Social Study of Health, Illness &amp; Medicine</i> 19(3) 263-279.						
McIlfatrick (2007) Assessing palliative care needs: views of patients, informal carers and healthcare professionals. <i>Journal of advanced nursing</i> 57(1) 77-86.				x		
McIlfatrick et al. (2014)						x
McQuillan et al (2007) Indigenous ethnic minorities and palliative care: exploring the views of Irish Travellers and palliative care staff. <i>Palliative medicine</i> 21(7) 635-641.	X	x				
Milligan, C et al. (2016) Unpacking the impact of older adults' home death on family care-givers' experiences of home. <i>Health &amp; Place</i> 38 103-111.	X					
Minto & Strickland (2011) Anticipating emotion: a qualitative study of advance care planning in the community setting. <i>International Journal of Palliative Nursing</i> 17(6) 278-284.					x	

Koffman & Higginson (2001) Accounts of carers satisfaction with health care at the end of life: A comparison of first generation black Caribbean and white patients with advanced disease. <i>Palliative Medicine</i> 15(4) 337-345.						x
Koffman et al (2014) Does Ethnicity Affect Where People with Cancer Die ? A Population-Based 10 Year Study. <i>Plos One</i> 9(4).			x	x		
Laird & Fallon. (2008) Palliative care in the elderly breast cancer patient. <i>Clinical oncology</i> 21(2) 131-139.				x		
Lawton (1998) Contemporary hospice care: the sequestration of the unbounded body and 'dirty dying'. <i>Sociology of health &amp; illness</i> 20(2) 121.	x	x	x			
Lowson et al. (2013) From 'conductor' to 'second fiddle': older adult care recipients' perspectives on transitions in family caring at hospital admission. <i>International Journal Of Nursing Studies</i> 50(9) 1197-1205.		x				
MacArtney et al. (2015) On resilience and acceptance in the transition to palliative care at the end of life. <i>Health: An Interdisciplinary Journal</i>					x	

Morris (2012) Advocating for palliative care for an ageing population: living to the end. <i>International Journal of Palliative Nursing</i> , 18, 420-421.			x			
Morris et al. (2015) Family carers providing support to a person dying in the home setting: A narrative literature review. <i>Palliative Medicine</i> 29(6) 487-495.		x				
Murtagh & Thorns. (2006) Evaluation and ethical review of a tool to explore patient preferences for information and involvement in decision making. <i>Journal of medical ethics</i> 32(6) 311-315.					x	
Needham & Newbury (2004) Goal setting as a measure of outcome in palliative care. <i>Palliative medicine</i> 18(5) 444-451.						x
Perrels et al. (2014) Place of death and end-of-life transitions experienced by very old people with differing cognitive status: Retrospective analysis of a prospective population-based cohort aged 85 and over. <i>Palliative Medicine</i> 28(3) 220-233			x	x		
Redman et al. (2008) Critical review of literature on ethnicity and health in relation to cancer and palliative care in the United Kingdom.						x

Kingdom. <i>Diversity in Health and Social Care</i> 5(2) 137-150.						
Rigby, Payne & Froggatt (2010) Review: what evidence is there about the specific environmental needs of older people who are near the end of life and are cared for in hospices or similar institutions? A literature review. <i>Palliative Medicine</i> 24(3) 268-285.	x					
Robinson et al. (2015) A qualitative study exploring the benefits of hospital admissions from the perspectives of patients with palliative care needs. <i>Palliative Medicine</i> 29(8) 703-710.	x					
Ryan et al. (2013) Symptom burden, palliative care need and predictors of physical and psychological discomfort in two UK hospitals. <i>BMC Palliative Care</i> 12 11-11.			x	x		
Schiff et al. (2008) Advance end-of-life healthcare planning in an acute NHS hospital setting: development and evaluation of the Expression of Healthcare Preferences (EHP) document. <i>Age &amp; Ageing</i> 38(1) 61-65					x	
Sharpe, K. H., et al. (2015). Policy for home or hospice as the preferred place of death from cancer: Scottish Health and Ethnicity Linkage Study population cohort shows challenges across all ethnic groups in Scotland. <i>BMJ Supportive &amp; Palliative Care</i> 5(4) 443-451.				x		

Seamark et al. (2014) Dying at home: A qualitative study of family carers views of support provided by GPs community staff. <i>British Journal of General Practice</i> 64(629)		x				
Seymour et al. (2007) Hospice or home? Expectations of end care among white and Chinese older people in the UK. <i>Sociology of health &amp; illness</i> 29(6) 872-890.	x	x				
Seymour, Almack, & Kennedy (2010) Implementing advance care planning: a qualitative study of community nurses' views and experiences. <i>BMC palliative care</i> 9(1) 4-4.					x	
Sutton & Coast (2012) 'Choice is a small word with a huge meaning': autonomy and decision-making at the end of life. <i>Policy &amp; Politics</i> 40(2) 211.		x				
Tomlinson, Barker, & Soden (2011) What are cancer patients' experiences and preferences for the provision of written information in the palliative care setting? A focus group study. <i>Palliative Medicine</i> 26(5) 760-765.						x

Thomas, Morris & Clark (2004) Place of death: preferences among cancer patients and their carers. <i>Social science &amp; medicine</i> 58(12) 2431-2444.		x				
Tuffrey, Wijne et al. (2009) The preferred place of care for people who are dying. <i>Learning Disability Practice</i> 12(6) 16-21.			x	x		
Venkatasalu et al. (2013) Talking about end-of-life care: the perspectives of older South Asians living in East London. <i>Journal of Research in Nursing</i> 18(5) 394-406.						x
Woods and Salter (2013) A time and place: what people want at end of life. Sue Ryder.	x	x				
Worth et al. (2009) Vulnerability and access to care for South Asian Sikh and Muslim patients with life limiting illness in Scotland: prospective longitudinal qualitative study. <i>BMJ</i> 338(feb03_1) b183.						x

<p>Williams et al. (2016)</p> <p>Because it's the wife who has to look after the man': A descriptive qualitative study of older women and the intersection of gender and the provision of family caregiving at the end of life. <i>Palliative Medicine</i>.</p>				x		
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# Appendix 7: NHS ethics approval 12/YH/0291



**Health Research Authority**  
**NRES Committee Yorkshire & The Humber - Sheffield**  
Yorkshire and the Humber REC Office  
First Floor, Millside  
Mill Pond Lane  
Meanwood  
Leeds  
LS8 4RA

Telephone: 0113 3050128

25 October 2012

Ms Fiona Wilson  
Doctoral Student  
Sheffield Hallam University  
Collegiate Campus  
Robert Winston Building  
Sheffield  
S10 2BP

Dear Ms Wilson

**Study title:** Choice and Decision-Making in Palliative Care: how do people make decisions about using hospice services?  
**REC reference:** 12/YH/0291  
**Protocol number:** nct 11/35

Thank you for your letter of 18 October 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

## Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

## Ethical review of research sites

### NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

### Non-NHS sites

## Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

# Appendix 8: NHS ethics approval of amendment (2014) 12/YH/0291



**Health Research Authority**

**National Research Ethics Service**

**NRES Committee Yorkshire & The Humber - Sheffield**

HRA NRES Centre Manchester  
Barlow House  
3rd Floor  
4 Minshull Street  
Manchester  
M1 3DZ

Tel: 0161 625 7832  
Fax: 0161 625 7299

12 September 2014

**Ms Fiona Wilson**  
Doctoral Student  
Sheffield Hallam University  
Collegiate Campus  
Robert Winston Building  
Sheffield  
S10 2BP

Dear Ms Wilson

<b>Study title:</b>	<b>Choice and Decision-Making in Palliative Care: how do people make decisions about using hospice services?</b>
<b>REC reference:</b>	<b>12/YH/0291</b>
<b>Protocol number:</b>	<b>nct 11/35</b>
<b>Amendment number:</b>	<b>1</b>
<b>Amendment date:</b>	<b>09 June 2014</b>
<b>IRAS project ID:</b>	<b>98356</b>

The above amendment was reviewed by the Sub-Committee in correspondence.

## **Ethical opinion**

Approval was sought to carry out interviews with health professionals and to access participant's medical notes to collect data. Approval was also sought to approach carers via the bereavement service.

The Committee advised that consent would need to be sought to access medical notes. The relevant documents were revised.

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

## **Approved documents**

The documents reviewed and approved at the meeting were:

# Appendix 9: University of Sheffield sponsorship University Research Management System (2012)



The  
University  
Of  
Sheffield.

The School Of  
Nursing  
And  
Midwifery.

Ms Fiona Wilson  
Faculty of Health and Wellbeing  
Sheffield Hallam University  
Collegiate Campus  
Robert Winston Building  
11-15 Broomhall Road  
Sheffield S10 4DN

Dean of School  
Professor Anne M Peat

School of Nursing and Midwifery  
Barber House  
887 Glossop Road  
Sheffield S10 2LJG

Telephone: +44 (0) 114 2220048  
Email: [f.wilson@sheffield.ac.uk](mailto:f.wilson@sheffield.ac.uk)

31 October 2012

**Project title: Choice and decision-making in palliative care: how do people make decisions about using hospice services?**  
**6 digit URMS number: 184386**

Dear Fiona,

**LETTER TO CONFIRM THAT THE UNIVERSITY OF SHEFFIELD IS THE PROJECT'S RESEARCH GOVERNANCE SPONSOR**

The University has reviewed the following documents:

1. A University approved URMS costing record;
2. Confirmation of independent scientific approval;
3. Confirmation of independent ethics approval.

All the above documents are in place. Therefore, the University now **confirms** that it is the project's research governance sponsor and, as research governance sponsor, **authorises** the project to commence any non-NHS research activities. Please note that NHS R&D approval will be required before the commencement of any activities which do involve the NHS.

You are expected to deliver the research project in accordance with the University's policies and procedures, which includes the University's Good Research Practice Standards: [http://www.sheffield.ac.uk/polopoly\\_fs/1.920481/files/research\\_standards.pdf](http://www.sheffield.ac.uk/polopoly_fs/1.920481/files/research_standards.pdf) and Ethics Policy: <http://www.sheffield.ac.uk/nhs/olhaec/gov-ethics/ethicspolicy>. If the project has received NHS ethics approval then you are also expected to publish a lay summary of the project on the website of the National Research Ethics Service (NRES), as it appears in the research ethics application.

2011  
**THE AWARDS**  
AWARD WINNER  
UNIVERSITY OF SHEFFIELD

## **Appendix 10: Study Pack**

## Appendix 10a: Contacts sheet



### The University of Sheffield

How do people make decisions about using hospice services?

**The above study may have raised some concerns for you. If there are specific aspects of your care that you feel you need to talk to someone about then please let the staff at St Luke's Therapies and Rehabilitation Unit or the Community team know as they may be able to help you. You may also find some of the contacts below useful:**

#### **The Cavendish Centre**

An independent local charity established nearly 20 years ago giving free emotional support to people and their families affected by cancer in Yorkshire and Derbyshire. The Centre offers a place for people to go to talk, and someone to help them deal with the way cancer has affected them and their life.

Website:

<http://www.cavcare.org.uk/>

Telephone 0114 2784600

#### **NHS Choices: Your Health: Your Choices**

This site provides a range of resources for different conditions and carer support. There is also a link for Carers Direct a free confidential, information and advice for carers telephone number which offers support on 0808 8020202

Website

<http://www.nhs.uk/CarersDirect/guide/bereavement/Pages/Bereavement-support.aspx>

#### **Age UK**

This is a useful site providing information and support around a range of issues for older people and their families and carers.

<http://www.ageuk.org.uk/>

0800 169 6565

#### **Cruse Bereavement Care**

National charity offering counseling, support, help and advice.

Helpline: 0844 477 9400

Young persons helpline: 0808 808 1677

Website: [www.crusebereavementcare.org.uk](http://www.crusebereavementcare.org.uk)

Fwv1contactdetails18-04-12

Email: [helpline@cruse.org.uk](mailto:helpline@cruse.org.uk)

### **BBC Health: Living with cancer**

List of organisations that offer help and support to cancer patients.

Website: [bbc.co.uk/health/support/cancer\\_usefulcontacts\\_index.shtml](http://bbc.co.uk/health/support/cancer_usefulcontacts_index.shtml)

### **If I Should Die.co.uk**

Useful website looking at all aspects of bereavement, and severe illness from the practical to the emotional.

Website: [www.ifishouldie.co.uk](http://www.ifishouldie.co.uk)

### **Samaritans**

Confidential emotional support for anyone in a crisis.

24-hour helpline: 0845 790 9090 (UK)

Website: [www.samaritans.org](http://www.samaritans.org)

### **The Child Bereavement Charity**

This charity aims to support families and professionals when a child is bereaved.

Website: [www.childbereavement.org.uk/](http://www.childbereavement.org.uk/)

Fwv1contactdetails18-04-12

## Appendix 10b: Flyers



### The University of Sheffield

How do people make decisions about using hospice services?

The above study aims to understand how people make decisions about their care and using hospice services. Making decisions can sometimes be difficult and understanding this experience may help to support patients and families.



If you are a service user or relative/carer of someone who receives hospice care, either through community services or through the Therapies and Rehabilitation Unit, and would be willing to share your experiences about how you came to use this service, I would be very pleased to hear from you.

The study would involve talking with Fiona Wilson, (a phd student and experienced nurse) for about an hour (or maybe less if you can't spare the time) about your experiences of how you came to use the hospice services.

If you are interested in taking part, an information pack is available, (please ask the staff). If you would like more information or if you would like to take part then please contact either myself as below or let one of the staff.

Thank you for your time in considering this study.



The University of Sheffield

## How do people make decisions about using hospice services?

The above study aims to understand how people make decisions about their care and using hospice services. Making decisions can sometimes be difficult and understanding this experience may help to support patients and families.

If you are a service user or relative/carer of someone who receives hospice care, either through community services or through the Therapies and Rehabilitation Unit, and would be willing to share your experiences about how you came to use this service, I would be very pleased to hear from you.

The study would involve talking with Fiona Wilson, (a phd student and experienced nurse) for about an hour (or maybe less if you can't spare the time) about your experiences of how you came to use the hospice services.

If you are interested in taking part, an information pack is available, (please ask the nursing staff). If you would like more information or if you would like to take part then please contact either myself as below or let one of the nursing staff know.

**Thank you for your time in considering this study.**

**Contact for further information:  
Fiona Wilson 0114 225 2247  
f.wilson@shu.ac.uk**

## Appendix 10c: Reply Slip



The University of Sheffield

**How do people make decisions about using hospice services?**

### Reply Slip

Please circle **YES**, or **NO** below and return in the stamped addressed envelope.

**YES** - I would be interested in finding out more about the above study and would be happy for Fiona Wilson to contact me to discuss further.

If yes, please provide your contact details as below:

**Name:**

.....

**Telephone number (or e-mail address if you prefer):**

.....

.....

**The best time to contact me is.....**

.....

**NO** - I am not interested in this study at the current time.

**Fiona Wilson**  
0114 225 2247  
[f.wilson@shu.ac.uk](mailto:f.wilson@shu.ac.uk)

**Thank you for your consideration.**



# Appendix 10d: Information sheet for clinical staff/patients/carers Version 2



The University of Sheffield

## Choice and Decision-Making in Palliative Care

### Information sheet for clinical staff

You are being invited to take part in a research study that aims to explore to what extent patients, their families and health professionals how choice and decision-making is understood and what concerns or expectations can influence decision-making in palliative care. Before you decide whether to participate please take time to read the following information and discuss it with your peers if you wish. Please ask if there is anything you would like more information about, or if anything is unclear.

#### **What is the purpose of the interview?**

The purpose of the interview is to explore how and what decisions are made about using palliative care services. The study is not about evaluating the hospice service.

I would like to ask you about your experiences of supporting patients and families who are accessing palliative care and in particular how choice and decision making is understood and supported and what concerns or expectations can influence care delivery.

#### **Why have I been chosen?**

You have been chosen because you are part of the clinical team at the St Luke's Hospice Therapies and Rehabilitation Unit/Community Services *[delete as appropriate]*. We are also inviting all patients who are currently receiving care from the St Luke's Hospice Therapies and Rehabilitation Unit/Community Services *[delete as appropriate]* to take part and would value the perspectives of clinical practitioners involved in supporting their care.

#### **Do I have to take part?**

It is entirely up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet and will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not have consequences.

#### **What will the interview involve?**

If you want to take part in the interview, it will involve speaking about your experiences to a trained interviewer for about an hour. Some participants might want to contact the researcher for a second interview if they wish to discuss further aspects of their experiences or to clarify any points. You might want to frame your discussion around a particular patient but any details will be anonymised to preserve confidentiality, whilst others might wish for a short single interview. You might find it useful to draw a diagram to map out what has influenced decisions, as this can be helpful to picture and reflect upon experiences. I have some examples to show you what I mean by this. Others prefer simply to talk through their experiences.

The interview can take place at your work place, or somewhere else of your choice. The interview will be digitally recorded and photographs of your map recorded with your permission. These recordings will be stored on a computer within the University

of Sheffield and only accessed by the project team with passwords and paper copies stored securely.

**What are the possible disadvantages and risks of taking part?**

We understand that people can sometimes get upset revisiting memories of their involvement with patients. However, you can finish the interview at any time and do not have to discuss any issues you do not want to. If you feel you require extra support after the interview, there is a list of helpful contacts or support from the clinical team.

**What are the possible benefits of taking part?**

This study aims to explore decision-making in using hospice services, and how this might inform how palliative care is delivered. There are no direct benefits to individuals but the study will aim to inform future palliative care service delivery.

**Will my taking part in this study be kept confidential?**

All information collected about you during the course of the interview will be kept strictly confidential. You will not be identified by name in any reports arising from the study and pseudonyms will be used. Anonymous extracts of your interview will be used for purposes of research dissemination. Recordings will be destroyed after a period of 12 months following completion of the study.

**What if something goes wrong?**

There are no specific risks associated with this study. However, if you have cause to complain about any aspect of your treatment while you are taking part in the study, the normal National Health Service complaints mechanism is available to you and you are not compromised in any way because you have taken part in a research study.

**What will happen to the results of the study, and who is organising it?**

The study is a doctoral study being undertaken by a student (Fiona Wilson) with research and palliative care experience and supported by supervisors with expertise in palliative care. The findings will be presented as part of a doctoral thesis. As part of the study outcomes the aim is to present findings to inform policy, practice, and report in academic and clinical journals and conferences. This study is based at the University of Sheffield. All research involving health care is looked at by an independent group of people, called a Research Ethics Committee (REC) to protect your safety, rights, wellbeing, and dignity. In addition, St Luke's Hospice has reviewed the study to ensure it meets with their quality standards. This study has been reviewed and given a favourable opinion by Sheffield REC.

**Will I find out the results of this study?**

Yes, when the study is complete I will provide an overview of the findings.

**What do I need to do now?**

Please return the reply slip to indicate if you would like to participate. There is a SAE envelope included so you don't need a stamp. If you return the reply slip I will contact you to arrange the interview and any questions you may have (you can change your mind about participating at this stage). Feel free to call me with any queries you may have and/or talk the study over with anyone else.

Fwinfosheetscs18-04v2

**Finally:**

**Thank you for your time in considering this study.**

**Contact for further information:  
Fiona Wilson 2252247**



The University of Sheffield

## Choice and Decision-Making in Palliative Care

### Information sheet for participants

You are being invited to take part in a research study, which aims to explore with patients, their families and health professionals how choice and decision-making is supported and what concerns or expectations can influence choice in palliative care. Before you decide whether to participate please take time to read the following information and discuss it with friends, relatives, and your doctor if you wish. Please ask if there is anything you would like more information about, or if anything is unclear.

#### **What is the purpose of the interview?**

The purpose of the interview is to explore how and what decisions are made about using palliative care services. The study is not about evaluating the hospice service.

I would like to talk about your experiences of using palliative care and what this has been like for you and your family. I would like to hear your thoughts and feelings about your experiences of palliative care including how you came to access this service and your expectations. I am very happy for you to have a family member or friend present during the interview, if you would prefer this.

#### **Why have I been chosen?**

You have been chosen as you are receiving care from the St Luke's Hospice Therapies and Rehabilitation Unit/Community Services *[delete as appropriate]*. We are inviting all patients who are currently receiving care from the St Luke's Hospice Therapies and Rehabilitation Unit/Community Services *[delete as appropriate]*.

#### **Do I have to take part?**

It is entirely up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet and will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

#### **What will the interview involve?**

If you want to take part in the interview, it will involve speaking about your experiences to a trained interviewer for about an hour. I would very much like to hear about your thoughts and experiences about using hospice services. Some people might find it useful to draw a diagram to map out what has influenced decisions, as this can be helpful to picture and reflect upon experiences. I have some examples to show you what I mean by this. Others prefer to simply talk through their experiences. Some participants might want to contact the researcher for a second interview if they wish to discuss further aspects of their experiences or to clarify any points, whilst others might wish for a short single interview. Just let me know how you would prefer to be interviewed. Again, the interview can take place at your home, over the telephone, or somewhere else of your choice. If you wish you might like to have a family member or friend present during the interview.

FWinfosheetV218-4-12

The interview will be digitally recorded and transcribed and I will take photographs of your map if you agree. These recordings will be stored on a computer within the University of Sheffield and only accessed by the project team with special passwords and paper copies stored in a secure deposit.

If you agree I would also like to interview a relative or friend who has been involved in supporting you to hear their experiences of palliative care. At the end of the interview I would like to give you my contact details and an information sheet to pass on to your relative or friend inviting them to take part in the study and they can contact me if they wish to find out more about the study. I fully understand if you decide this would not be appropriate.

It would also be of value to understand how health professionals involved in your care how have supported you and if you agree I would like to discuss your case confidentially. If you do not feel this would be appropriate I fully understand.

**What are the possible disadvantages and risks of taking part?**

We understand that people can sometimes get upset talking about their health. However, you can finish the interview at any time and do not have to discuss any issues you do not want to. If you feel you require extra support after the interview, we will contact one of your healthcare team, with your permission. A list of helpful contacts can be provided.

**What are the possible benefits of taking part?**

This study aims to explore decision-making in using hospice services, and how this might inform how palliative care is delivered. There are no direct benefits to individuals but the study will aim to inform future palliative care service delivery.

**Will my taking part in this study be kept confidential?**

All information collected about you during the course of the interview will be kept strictly confidential. You will not be identified by name in any reports arising from the study and information you provide will only be shared with members of our research team. Anything you tell us during your interview will be strictly confidential and not shared with anyone, including your doctors/nurses. A recording of your interview will be kept in a locked filing cabinet at the University of Sheffield and only accessed by members of the research team. We may use short anonymous extracts of your interview for purposes of research dissemination, but any use of your interview will be made completely anonymous. Recordings will be destroyed after a period of 12 months following completion of the study.

**What if something goes wrong?**

There are no specific risks associated with this study. However, if you have cause to complain about any aspect of your treatment while you are taking part in the study, the normal National Health Service complaints mechanism is available to you and you are not compromised in any way because you have taken part in a research study. If you identify that an area of care is causing you great concern then it might be appropriate for the researcher to suggest that you contact your health care team or other support agency.

**What will happen to the results of the study, and who is organising it?**

The study is a doctoral study being undertaken by a student (Fiona Wilson) with research and palliative care experience and supported by supervisors with expertise in palliative care. The findings will be presented as part of a doctoral thesis. As part of the study outcomes the aim is to present findings to inform policy, practice, and research and report in academic and clinical journals and conferences. This study is based at the University of Sheffield. All research involving health care is looked at by an independent group of people, called a Research Ethics Committee (REC) to protect your safety, rights, wellbeing, and dignity. In addition, St Luke's Hospice has reviewed the study to ensure it meets with their quality standards. This study has been reviewed and given a favourable opinion by Sheffield REC.

**Will I find out the results of this study?**

Yes, when the study is complete I will provide an overview of the findings.

**What do I need to do now?**

Please return the reply slip to indicate if you would like to participate. There is a SAE envelope included so you don't need a stamp. If we receive a reply slip I will contact you by telephone to arrange the interview and answer any questions you may have (you can change your mind about participating at this stage). Feel free to call me with any queries you may have and/or talk the study over with anyone else.

**Finally:**

**Thank you for your time in considering this study.**

**Contact for further information:  
Fiona Wilson 0114 225 2247  
f.wilson@shu.ac.uk**



## The University of Sheffield

### How do people make decisions about using hospice services?

#### **Information sheet for Family Carers/Friends**

You are being invited to take part in a research study that aims to explore with patients, their families/carers and health professionals what influences how decisions are made about using hospice services. Before you decide whether to participate please take time to read the following information and discuss it with friends, relatives, and your doctor if you wish. Please ask if there is anything you would like more information about, or if anything is unclear.

#### **What is the purpose of the interview?**

The purpose of the interview is to explore how and what decisions are made about using palliative care services. The study is not about evaluating the hospice service.

I would like to talk about your experiences of using palliative care and what this has been like for you and your family. I would like to hear your thoughts and feelings about your experiences of palliative care including how you came to access this service and your expectations. I am very happy for you to have a family member or friend present during the interview, if you would prefer this.

#### **Why have I been chosen?**

You have been chosen as you are supporting someone receiving services at the St Luke's Hospice Therapies and Rehabilitation Unit/Community Services *[delete as appropriate]*. This person has indicated that they happy for us to approach you as someone who may provide a carer perspective around choice and decision making in palliative care.

#### **Do I have to take part?**

It is entirely up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet and will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you and your relative/friend receive.

#### **What will the interview involve?**

The interview will involve speaking about your experiences to a trained interviewer for about an hour about your thoughts and experiences about using hospice services. Some people might find it useful to draw a diagram to map out what has influenced decisions, as this can be helpful to picture and reflect upon experiences. I have some examples to show you what I mean by this. Others prefer to simply talk through their experiences. Some participants might want to contact the researcher for a second interview if they wish to discuss further aspects of their experiences or to clarify any points, whilst others might wish for a short single interview. Just let me know how you would prefer to be interviewed. Again, the interview can take place at

Fwinfosheetfc18-4-12V2

your home, or somewhere else of your choice. If you wish you might like to have a family member or friend present during the interview.

The interview will be digitally recorded and transcribed and copies of your diagram/map recorded if you agree. These recordings will be stored on a computer within the University of Sheffield and only accessed by the project team with special passwords and paper copies stored in a secure deposit

**What are the possible disadvantages and risks of taking part?**

We understand that people can sometimes get upset talking about their experiences. However, you can finish the interview at any time and do not have to discuss any issues you do not want to. If you feel you require extra support after the interview, we will contact one of the healthcare team, with your permission. A list of contacts can be provided.

**What are the possible benefits of taking part?**

This study aims to explore decision-making in using hospice services, and how this might inform how palliative care is delivered. There are no direct benefits to individuals but the study will aim to inform future palliative care service delivery.

**Will my taking part in this study be kept confidential?**

All information collected about you during the course of the interview will be kept strictly confidential. You will not be identified by name in any reports arising from the study and pseudonyms will be used. Anonymous extracts of your interview will be used for purposes of research dissemination. Recordings will be destroyed after a period of 12 months following completion of the study.

**What if something goes wrong?**

There are no specific risks associated with this study. However, if you have cause to complain about any aspect of your treatment while you are taking part in the study, the normal National Health Service complaints mechanism is available to you and you are not compromised in any way because you have taken part in a research study.

**What will happen to the results of the study, and who is organising it?**

The study is a doctoral study being undertaken by a student (Fiona Wilson) with research and hospice care experience and supported by supervisors with expertise in palliative care. The findings will be presented as part of a doctoral thesis. As part of the study outcomes the aim is to present findings to inform policy, practice, and report in academic and clinical journals and conferences. This study is based at the University of Sheffield. All research involving health care is looked at by an independent group of people, called a Research Ethics Committee (REC) to protect your safety, rights, wellbeing, and dignity. In addition, St Luke's Hospice has reviewed the study to ensure it meets with their quality standards. This study has been reviewed and given a favourable opinion by Sheffield REC.

**Will I find out the results of this study?**

Yes, when the study is complete I will provide an overview of the findings.

**What do I need to do now?**

Please return the reply slip to indicate if you would like to participate. There is a SAE envelope included. If I receive a reply slip I will contact you by telephone to arrange the interview and answer any questions you may have (you can change your mind about participating at this stage). Feel free to call me with any queries you may have and/or talk the study over with anyone else.

**Finally:**

**Thank you for your time in considering this study.**

**Contact for further information:  
Fiona Wilson 225 2247  
f.wilson@shu.ac.uk**

## Appendix 10e: Consent form



The University of Sheffield

How do people make decisions about using hospice services?

Please read and initial each box if you agree to each point.

1.	I confirm I've read the information sheet for the above interview (V2dated18-4-12). I've had the opportunity to consider the information, ask questions and have had these answered. .	<input type="checkbox"/>
2.	I understand that my participation is voluntary and that I'm free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected . . . . .	<input type="checkbox"/>
3.	I agree to the interview being digitally recorded. . . . . -	<input type="checkbox"/>
4	I agree to a further interview if required	<input type="checkbox"/>

\_\_\_\_\_  
Name of Participant                      Date                      Signature

\_\_\_\_\_  
Researcher                      Date                      Signature

Fwconsentfrm218-04-12

## Appendix 11: Study Pack- (Urdu)



### یونیورسٹی آف سالفورڈ

لوگ ہوسپس کی سروس استعمال کرنے کے بارے میں فیصلے کیسے کرتے ہیں؟

#### ی شیڈول:

میں یہ جانتے میں دلچسپی رکھتی ہوں کہ آپ یہ بتائیں کہ ہوسپس کیئر سروسز استعمال کرنے کے فیصلے میں آپ کی کس نے اور کیا مدد کی اور یہ آپ کے لئے کیسا رہا ہے۔

اس سے پیشتر کہ ہم شروع کریں، یہ مفید ہوگا کہ ہم میں منظر کی کچھ معلومات حاصل کریں۔ کیا آپ مندرجہ ذیل سوالات کے جوابات دیں گے؟

1. کیا میں آپ کی عمر یوجہ سکتی ہوں (اگر آپ بڑا نہ منائیں تو؟)	
2. جنس	
3. آپ اپنی ازدواجی حیثیت کو کیسے بیان کریں گے (غیر شادی شدہ، طلاق یافتہ، شادی شدہ)	
4. آپ اپنی نسلی اصلیت کو کیسے بیان کریں گے؟	
5. کیا آپ مجھے اپنی اعلیٰ ترین تعلیمی قابلیت کا درجہ بتائیں گے؟ (مثلاً جی سی ایس ای یا او لیول، اے لیول، گگری، پیشہ ورانہ یا آکریڈیشنل قابلیت کا معیار)	
6. آپ کا پیشہ کیا تھا یا کیا ہے؟	
7. کیا آپ کے ساتھ کوئی رہتا ہے؟ اگر ہاں، تو کون؟ (اور ان کا آپ کے ساتھ کیا رشتہ ہے؟)	ی /
8. کیا میں یوجہ سکتی ہوں کہ ان کی عمریں کیا ہیں؟	
9. کیا آپ کے خاندان کے کوئی ایسے افراد یا دوست ہیں جو آپ کے نزدیک رہتے ہیں؟	
10. کیا آپ کے بچے ہیں؟	
11. وہ کتنے ہیں اور ان کی عمریں کیا ہیں؟	
12. آپ کس کے بارے میں کہیں گے کہ وہ آپ کو تعاون اور مدد مہیا کرتا ہے؟ (یا تو جذباتی تسکین یا جسمانی دیکھ بھال کے ساتھ مدد)۔	ی کہ دوست، ی
13. آپ سینٹ لیوکس کی طرف سے کب سے دیکھ بھال وصول کر رہے ہیں؟	
14. کیا آپ بتا سکتے ہیں کہ آپ کی موجودہ حالت کی سب سے پہلے تشخیص کب ہوئی تھی؟	



یونیورسٹی آف شیفلڈ

## لوگ بوسپس (مریض خانے) کی خدمات استعمال کرنے کے بارے میں فیصلے کیسے کرتے ہیں؟

عزیز (برائے کرم نام لکھیں)،

آپ کو ایک مطالعہ (اسٹڈی) میں حصہ لینے کے لئے دعوت دی جا رہی ہے جس کا مقصد یہ سمجھنا ہے کہ لوگ اپنی دیکھ بھال اور مریض خانے (بوسپس) کی خدمات استعمال کرنے کے فیصلے کیسے کرتے ہیں۔ آپ کے رشتہ دار یا دوست نے اظہار کیا ہے کہ انہیں خوشی ہوگی اگر آپ میرے ساتھ اپنے تجربات کے بارے میں بات چیت کریں۔

فیصلے کرنا بعض اوقات مشکل ہو سکتا ہے۔ اس بارے میں جاننا کہ لوگ فیصلے کیسے کرتے ہیں، مریضوں اور گھنوں کو تعاون فراہم کرنے میں مدد کر سکتا ہے۔ آپ کے تجربات یہ سمجھنے میں مددگار ہونگے کہ لوگ بوسپس کی خدمات استعمال کرنے کے لئے ان سے کیسے متعارف ہوئے ہیں۔

اس مطالعہ میں اس بارے میں میرے ساتھ یعنی کہ فیونا ولسن (ایک پی ایچ ڈی کی طالبہ اور تجربہ کار نرس) کے ساتھ ایک گھنٹے تک (یا اگر آپ وقت نہیں نکال سکتے تو اس سے کم) آپ کے تجربات کے بارے میں بات چیت کرنا شامل ہوگا کہ آپ بوسپس (یا تو کمیونٹی سروس یا ری ہیبیلی ٹیشن اینڈ تھراپیز یونٹ) کی خدمات استعمال کرنے کے لئے ان سے کیسے متعارف ہوئے ہیں۔

اگر آپ حصہ لینے کے بارے میں مزید جاننا چاہتے ہیں یا اس پر مزید تفصیل کے ساتھ میرے ساتھ بات کرنا چاہتے ہیں تو آپ اس خط کے ساتھ بھیجی جانے والی معلوماتی ٹیٹ یٹھ سکتے ہیں یا مجھ سے [f.wilson@shu.ac.uk](mailto:f.wilson@shu.ac.uk) پر رابطہ کر سکتے ہیں (یا 0114 2252247 پر ٹیلی فون کریں) اور مجھے آپ کی بات سن کر بہت خوشی ہوگی۔

اگر آپ سمجھتے ہیں کہ آپ حصہ لینا چاہیں گے تو برائے کرم جوابی سلب پر پتہ لکھ کر اس خط کے ساتھ بھیجے گئے لفافے (جس پر ٹکٹ لگانے یا پتہ لکھنے کی ضرورت نہیں ہے) میں واپس بھیج دیں اور میں آپ سے یہ وضاحت کرنے کے لئے رابطہ کرونگی کہ اس مطالعہ میں کیا شامل ہوگا اور آپ سے ملاقات کے لئے وقت کا انتظام کرونگی۔

میں جانتی ہوں کہ اپنے تجربات کے بارے میں بات چیت کرنا پریشان کن ہو سکتا ہے۔ اس تحقیقی عمل میں حصہ لینا ضروری نہیں ہے اور آپ کا فیصلہ کسی بھی طرح آپ کی دیکھ بھال پر اثر انداز نہیں ہوگا۔ اگر آپ حصہ نہیں لینا چاہتے، تو برائے کرم اس معلوماتی ٹیک نظر انداز کر دیں اور میں آپ کے اس سلسلے میں غور کرنے پر آپ کی تسکین گزار ہوں۔

اس مطالعہ کے بارے میں غور کرنے کے لئے وقت نکالنے کا شکریہ .

آپ کی مخلص

فیونا ولسن

مزید معلومات کے لئے رابطے کی تفصیلات:

فیونا ولسن 0114 225 2247

[f.wilson@shu.ac.uk](mailto:f.wilson@shu.ac.uk)

میں ہوسیس کی سروس تک رسائی کے بارے میں آپ کے خیالات اور تجربات کے بارے میں جاننا پسند کرونگی۔ ہوسکتا ہے کہ کچھ لوگ اس بات کا اظہار کرنے کہ ان کے فیصلوں پر کون سے امور اثر انداز ہوئے، کاغذ پر خاکے بنانا کارآمد جائیں کیونکہ اس طرح ان کو اپنے تجربات کی عکاسی کرنے میں مدد مل سکتی ہے۔ میں یہ دکھانے کے لئے کچھ مثالیں مہیا کر سکتی ہوں کہ اس سے میری کیا مراد ہے۔ دیگر افراد شاید سادہ انداز میں اپنے تجربات کے بارے میں صرف بات کرنے کو ترجیح دیں۔ اگر آپ محسوس کریں کہ آپ کے تاثرات کو خاکوں کی صورت میں ترتیب دینے میں مدد ملے گی تو مجھے بتائیے۔

#### موضوع ۱: شعور اور توقعات:

سینٹ لیوکس کے ساتھ واسطہ پڑنے سے بیشتر ہوسیس کے بارے میں عمومی طور پر آپ کے خیالات اور احساسات کیا تھے:

تجویز: آپ کیا سمجھتے تھے کہ ہوسیس کس طرح کا ہوگا؟ آپ ہوسیس کی دیکھ بھال کے بارے میں ذہن میں کیا خیالات رکھتے تھے؟ وہ خیالات آپ کے لئے کتنی اہمیت رکھتے تھے؟ کیا آپ کے ہوسیس سے متعارف ہونے کے ردعمل میں ان خیالات کا عمل دخل تھا؟

موضوع ۲: تکلیف میں کمی کے لئے دیکھ بھال کی خدمات (پیلی ایڈوکیٹرسروسز) تک رسائی حاصل کرنا کیا آپ مجھے بتا سکتے ہیں کہ آپ کو کمیونٹی ٹیم / تھراپیٹسٹ اینڈ ری ہیبیلیٹیشن ڈے یونٹ سے رجوع کیسے کروایا گیا؟

کیا کوئی خاص بات تھی جو اجاگر واقع ہوئی اور یہ ریفرل یعنی رجوع کروایا گیا؟ کیا آپ رجوع کروائے جانے کے فیصلے میں شامل تھے؟

#### ترغیب:

آپ سینٹ لیوکس کی سروس (کمیونٹی یا تھراپیٹسٹ اینڈ ری ہیبیلیٹیشن یونٹ) کے ساتھ سب سے پہلے رابطہ کیسے ہوا؟۔ شاید دوستوں کے ذریعے، جی بی ریفرل کے ذریعے۔

کیا آپ کو یاد ہے کہ جب آپ کو ہوسیس کی سروس سے رجوع کروایا گیا تو آپ نے کیا محسوس کیا؟

کیا آپ کو اس بارے میں کوئی اختیار تھا کہ آپ کو رجوع کروایا جانا چاہئے؟

اپنی دیکھ بھال کے لئے آپ نے کس امر کو اپنے آپ کے لئے بہترین سمجھا؟

کیا سروس استعمال کرنے کے بارے میں آپ کو کوئی خدشات یا پریشانیوں لاحق تھیں؟

#### موضوع ۳: دیکھ بھال کرنے والے (کینئر) / رشتہ دار کی طرف سے مدد:

آپ کا سینٹ لیوکس کی سروس کے لئے رجوع کینے جانے کے بارے میں آپ کے رشتہ دار/ دیکھ بھال کرنے والے کیا سوچتے ہیں؟

ترغیب: کیا آپ ہوسیس کی سروس استعمال کرنے کے بارے میں اپنے رشتہ دار/ دیکھ بھال کرنے والے سے بات چیت کر سکتے تھے؟ کیا یہ ان کی تجویز تھی؟ وہ اس کے بارے میں کیا محسوس کرتے ہیں؟

کیا ان کو آپ کے رجوع کیئے جانے کے بارے میں خدشات و تحفظات تھے؟

ان کی نظر میں آپ کے لئے اس وقت مناسب ترین حکمت عملی کیا تھی؟

کیا کوئی آپ کو تعاون فراہم کرنے کے قابل تھا؟ (رشتہ دار، کوئی ہیلتھ کیئر پروفیشنل یا خیراتی ادارہ یا ویب سائٹ) یا کیا کسی چیز نے آپ کی مدد کی؟

#### موضوع ۴. شناخت:

ہوسیس سے رجوع کینے جانے کے بعد کیا آپ کے اپنے کنبے / دوستوں سے تعلقات یا آپ کے اپنے کنبے میں مقام پر کوئی اثر پڑا ہے؟

#### ترغیب:

کیا آپ نہ بتانے کو ترجیح دیتے ہیں؟

کیا آپ فکر مند ہیں کہ لوگوں کا ردعمل کیا ہوگا؟ کیا آپ بتا سکتے ہیں کہ کیوں؟

#### موضوع ۵. معلومات دینے (یا وصول کرنے) میں مشکلات.

<p>(ہاں/ نہیں) میں اپنی رابطے کی تفصیلات اور ایک معلوماتی سٹیٹ آپ کو مہیا کرونگی تاکہ آپ وہ اپنے رشتہ دار/ دوست تک پہنچا دیں۔ اگر وہ حصہ لینا چاہیں تو مجھ سے رابطہ کر سکتے ہیں۔</p>	<p>15. میں یہ جاننا چاہونگی کہ آپ کے رشتہ دار/ دوست نے ہوسیس کی سرویس کو استعمال کرنے کے تجربے کو کیسا پایا ہے۔ کیا آپ اس بات پر رضامند ہونگے کہ میں آپ کے رشتہ دار/ دوست کے ساتھ بات کروں؟</p>
<p>ہاں/ نہیں</p>	<p>16. کیا آپ اس بات پر رضامند ہونگے کہ میں آپ کی دیکھ بھال میں ملوث صحت سے متعلق ماہرین کے ساتھ اس بارے میں بات کروں کہ انہوں نے آپ کے فیصلوں میں آپ کی کیسے مدد کی ہے؟</p>

جب آپ کو پہلی دفعہ رجوع کروایا جا رہا تھا تو کیا آپ کو اپنے احساسات کے بارے میں بات کرنے اور ہوسپس کی خدمات کو استعمال کرنے کے بارے میں سوالات پوچھنے کا موقع ملا تھا؟  
**تجویز:** آپ نے کس کے ساتھ بات کی؟  
 کیا کسی سے بات کرنا مفید ثابت ہوا؟  
 کیا آپ سوالات پوچھ سکتے تھے؟  
 کیا وہ معلومات جو آپ کو دی گئی تھیں قابل فہم تھیں؟

**بعض لوگ اپنی مستقبل کی دیکھ بھال کے بارے میں بات کرنے میں دقت محسوس کرتے ہیں، لیکن کیا آپ نے محسوس کیا کہ آپ مستقبل کی دیکھ بھال کے بارے میں باآسانی بات کر سکتے اور سوالات پوچھ سکتے؟**  
 کیا آپ نے پریفرنڈ پریپاریشنز آف کیئر (دیکھ بھال کی اہم ترین ترجیحات) نامی دستاویز کے بارے میں سنا ہے یا اس دستاویز کو استعمال کیا ہے؟  
 اگر آپ نے اس دستاویز کو استعمال کیا ہے تو کیا آپ سمجھتے ہیں کہ یہ مددگار ثابت ہوئی؟

(تحقیق کنندہ یہی سی دستاویز کی ایک مثال مہیا کرتا ہے) اگر آپ نے یہ دستاویز استعمال نہیں کی ہے تو کیا آپ سمجھتے ہیں کہ یہ آپ کے لیئے مددگار ثابت ہوگی یا نہیں؟  
 کیا آپ بتا سکتے ہیں کہ کیوں؟  
 کیا آپ سمجھتے ہیں کہ مستقبل کی دیکھ بھال کی منصوبہ بندی کرنا مددگار ثابت ہو سکتا ہے؟ کیا آپ بتا سکتے ہیں کیوں (یا کیوں نہیں)؟

**موضوع ۴۔ سوچ و سمجھ میں تضاد**  
 اگر آپ سینٹ ٹوکس کے بارے میں اپنے تجربات کی روشنی میں ایک لمحے کے لیے سوچیں تو آپ ان کا اپنی توقعات کے مقابلے میں کیسے موازنہ کریں گے؟  
 تجویز:

کیا آپ کسی اور قسم کی سروس کو ترجیح دیتے؟  
 کیا خاص طور پر کوئی ایسی چیز تھی جس کے بارے میں آپ نے سوچا کہ وہ مختلف ہوگی؟  
 جب عملے کے افراد آپ کو اس سروس اور دیکھ بھال کے بارے میں سمجھا رہے تھے تو کیا آپ اسے باآسانی سمجھ پائے؟

آپ کسی ایسے شخص کو جسے آپ کی طرح پہلی ایٹو کیئر ٹیم کی خدمات کی ضرورت پڑے اپنے ذاتی تجربے کی روشنی میں کیا مشورہ دیں گے۔  
 آپ کو صورت حال سے نپٹنے میں کیا مددگار ثابت ہوا ہے؟  
**اور آخر میں:**

اپنے وقت اور اپنے تجربات کے بارے میں بات کرنے کا شکریہ۔ اس سے بیشتر کہ ہم ختم کریں، کیا کوئی ایسی بات ہے جس کو سمجھنے کی مجھے کوشش کرنا چاہیے اور جس کا ہم نے احاطہ نہیں کیا ہے؟  
 اگر کوئی ایسی بات ہے جس کو آپ شامل کرنا چاہیں گے اور جس کے بارے میں ہم نے آج نہیں سوچا ہے، تو برائے کرم مجھ سے آزادانہ طور پر رابطہ کریں۔  
 آپ نے مجھے ان معاملات کو سمجھنے میں مدد کے لیے جن امور پر بات کی ہے اگر میں ان کے بارے میں مزید وضاحت کے لیے آپ سے دوبارہ رابطہ کروں تو آپ بُرا محسوس تو نہیں کریں گے؟



یونیورسٹی آف شیفلڈ

## لوگ ہوسپس (مریض خانے) کی خدمات استعمال کرنے کے بارے میں فیصلے کیسے کرتے ہیں؟

براہ کرم نیچے ہاں یا نہیں کے گرد دائرہ لگائیں اور اسے مہیا کردہ پتہ لکھے اور ٹکٹ  
لگے لفافے میں واپس بھیج دیں۔

ہاں۔ میں مندرجہ بالا تحقیق کے بارے میں مزید جاننے میں دلچسپی رکھتا / رکھتی ہوں اور  
بخوشی جاہونگا / گی کہ فیونا ولسن مزید بات چیت کے لئے مجھ سے رابطہ کرے۔

میرے ساتھ رابطے کا سب سے بہتر وقت ہے .....

نام: .....

.....

ٹیلی فون نمبر: .....

.....

نہیں۔ میں اس وقت اس تحقیق میں دلچسپی نہیں رکھتا / رکھتی۔

آپ کے غور کرنے کا شکریہ۔

اگر آپ چاہیں تو مجھ سے درج ذیل تفصیلات استعمال کرتے ہوئے رابطہ کر سکتے ہیں:  
فیونا ولسن

0114 225 2247

f.wilson@shu.ac.uk

# Appendix 12: Interpreters Witness Statement

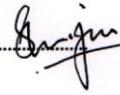
## STATEMENT OF WITNESS

Statement of  
Age of Witness  
Occupation of Witness  
Address

Shahjehan Shan  
01-01-1958  
Translator  
TheBigWord, Link Up House, Ring Road, Lower  
Wortley, Leeds, UK, LS12 6AB

This statement, consisting of 1 page signed by me, is true to the best of my knowledge and belief and I make it knowing that, if it is tendered in evidence, I shall be liable to prosecution if I have wilfully stated in it anything which I know to be false or do not believe to be true.

Dated the 29th day of January, 2013.

(signed) .....

I have been a translator for 08 years and translate texts from English into Urdu. I have a Masters in English Language and Literature from Punjab University, Pakistan.

I have been shown a copy of the following documents in English and have translated them into Urdu

CC11159463

(signed) .....

## **Appendix 13: Interview Schedules**

## Appendix 13a: Interview schedule for clinical staff. Version 2



The University of Sheffield

How do people make decisions about using hospice services?

### Interview Schedule: Clinical Staff

I am interested in your experiences of supporting patients in palliative care. It might be useful to think about a particular patient or someone else you have been involved with. Some people find it useful to map out and reflect on their experiences.

Before we start can I ask you a few questions about yourself?

1. Can I ask what your role is within palliative care? (Staff nurse, community nurse, medic)	
2. How long you have been working in this field?	
3. Do you have specialist palliative care qualifications? (please give details)	
4. Gender	

Some people might find it useful to draw a diagram to map out what has influenced decisions, as this can be helpful to picture and reflect upon experiences. I can provide some examples to show you what I mean. Others prefer simply to talk through their experiences. Let me know if you think it would be helpful to draw out your experiences.

**Theme 1. Perceptions and Expectations:**

**Theme 2. Accessing palliative care services:**

**Theme 3. Carer/Relative Support:**

**Theme 4. Identity:**

**Theme 5. Challenges to information giving (and receiving)**

**Theme 6. Dissonance in understandings**

**Theme 1. Perceptions and Expectations:**

What sort of expectations do patients have when they are first referred to the service?

**Prompt:** How do you explain the service?

Are there difficulties in approaching patients and families/carers in suggesting palliative care services?

What options are considered?

Interviewschedulev2cs18-04-12

What sort of reactions do you anticipate?  
Are expectations realistic?

**Theme 2. Accessing palliative care services:**

**Patient choice in accessing palliative care services is encouraged in the End of Life Care strategy. What are your thoughts on this approach?**

**Prompt:** How do patients generally come into contact with your service?  
How do you and the clinical team support patient's choice?  
What sort of choices are available?

What issues arise when someone chooses an approach to his or her care (such as not wishing to visit the day unit), which you feel is inappropriate?  
What would make you concerned? Do you have any examples?  
What sort of advice would you give someone new to a professional role in the community service/therapies and rehabilitation service in supporting patient choice?

**Theme 3. Relative/Friend Support:**

**How important are relatives and friends in supporting choice?**

**Prompt:** Do relatives and patients agree on choice and decisions? Have you experiences where patients and those that have supported them, have agreed on care decisions? Or disagreed? Do you have any examples?  
How did the clinical team manage differences in opinion? (Either between staff or patients and relatives, or between families and staff)

**Theme 4. Identity:**

**How does palliative care impact on a patient's identity?**

**Prompt:** How do people respond to the service- do you think it changes their perception of themselves? Does it change their relationships with their friends/family?  
Do you have any examples?

**Theme 5. Challenges to information giving (and receiving)**

Patient choice suggests that patients should have information about services and their care. **How do you decide what information is appropriate to give and to whom and when?**

**Prompt:** What factors might make giving information straightforward or difficult.  
Have you heard of the Preferred Priorities of Care document?  
Do you think this is a useful or appropriate document with which to support patient choice?  
Do you think that planning for care in the future is helpful? Can you say why (or why not)?

**Theme 6. Dissonance in understandings**

**Do you think patients' experience of St Luke's matches the expectations those patients had prior to referral?**

**Prompt:** Perhaps relatives or patients feel that hospice care is the end, or offers euthanasia?

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What do you think patients and relatives/carers expect from you?

Supporting people and their relatives/friends in their care, and choices must be very complex. Is there anything we haven't discussed that you think would be important to consider?

Thank you for your time and sharing your story. Before we finish is there anything that I should try to understand that we haven't covered?

If you think of anything else you would like to add that we haven't thought of today, please feel free to contact me.

Would you mind if I were to come back and clarify any points you have made to help my understanding?

## Appendix 13b: Interview schedule for patient participants. Version 2



The University of Sheffield

How do people make decisions about using  
hospice services?

### Interview schedule: Participants

I am interested in what or who helped you to make the decision to use the hospice care services and how that has been for you.

Before we start it would be useful to have some background information. Would you mind completing the following questions?

1 Can I ask you your age (if you don't mind?)	
2. Gender	
3. How would you describe your marital status (single, divorced, married)	
4. How would you describe your ethnicity?	
5. Would you mind telling me your highest level of educational qualification? (for example, GSCE or O level, A level, degree, professional or occupational qualification)	
6. What was or is your occupation?	
7. Does anyone live with you? If yes, who? (And what relationship do they have to you?)	Yes/No
8. Can I ask how old they are?	
9. Do you have family and friends who live close by?	
10. Do you have children?	
11. How many and how old?	
12. Who would you say provides you	i.e. friend, neighbour, family relative

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with support and help? (Either emotional support or support with physical care)	
13. How long have you been receiving care from St Luke's?	
14. Can you remember when your current condition was first diagnosed?	
15. I would be interested in hearing how your relative/friend has found the experience of using the hospice services. Would you be willing for me to talk to your relative/friend?	(Yes/No) I will leave my contact details and an information sheet with you to pass on to your relative/friend. If they wish to take part they can contact me.
17. Would you be willing for me to talk to one of the health professionals involved in your care about how they have supported your decisions?	Yes/No

I would very much like to hear your own thoughts and experiences about accessing the hospice service. Some people might find it useful to draw a diagram to map out what has influenced decisions, as this can be helpful to picture and reflect upon experiences. I can provide some examples to show what I mean by this. Others prefer simply to talk through their experiences. Let me know if you think it would be helpful to draw out your experiences.

**Theme 1. Perceptions and Expectations:**

**What were your thoughts and feelings about hospice care generally before you ever came into contact with St Luke's?**

**Prompt:** What did you think a hospice might be like? What images did you have of hospice care? What did those images mean to you? Did it shape how you responded to the hospice?

**Theme 2. Accessing palliative care services:**

Can you tell me about how you came to be referred to the community team/therapies and rehabilitation day unit?

Was there anything in particular that triggered the referral?

Were you involved in the decision to be referred?

**Prompt:**

When did you first come into contact with the St Luke's services (community or therapies and rehabilitation unit)? -Possibly through friends, GP referral  
Can you remember how you felt about being referred to the hospice services?  
Did you have any choice about whether you wanted to be referred?  
What did you see as your best options for care?  
Did you have any concerns or worries about using the service?

**Theme 3. Carer/Relative Support:**

**What did your relatives/carers think you about you being referred to St Luke's services?**

**Prompt:** Were you able to talk to your relative/carer about using the hospice service? Was it their idea? How do they feel about it?  
Did they have any concerns or worries about you being referred?  
What did they think were the best options for you at this time?  
Was anyone able to support you? (relative, health care professional or charity organisation or website ) or did anything help you?

**Theme 4. Identity:**

**Has being referred to the hospice changed your relationships with family/friends, or your place in your family?**

**Prompt:**

Do you prefer not to tell people?

Are you worried by people's reactions? Can you say why?

**Theme 5. Challenges to information giving (and receiving).**

**Just looking back to when you were first referred did you have the opportunity to talk about your feelings and ask questions about using hospice services?**

**Prompt:** Whom did you talk to?  
Was it useful to talk to someone?  
Were you able to ask questions?  
Did the information you were given make sense?

**Some people find it difficult to talk about their future care, but have you felt able to talk about and ask questions about future care?**

Have you heard of the Preferred Priorities of Care document or used this document?

If you used this document did you think it was helpful?

*(Researcher supplies an example of the PPC document)* If you haven't used this document do you think you would find it helpful or not?

Can you say why?

Do you think that planning for care in the future is helpful? Can you say why (or why not)?

**Theme 6. Dissonance in understandings**

**Just reflecting for a moment, how do your experiences of St Luke's match your expectations of what you thought the service would be like?**

**Prompt:**

Would you have preferred another type of service?

Was there anything in particular you thought would be different?

Did you find it easy to understand what staff were saying to you when explaining services and care?

**After all your experiences what advice would you give someone in the same boat as you when you first needed the palliative care team?**

**What helps you to cope?**

**Finally:**

Thank you for your time and sharing your experiences. Before we finish is there any thing that I should try to understand that we haven't covered?

If you think of anything else you would like to add that we haven't thought of today, please feel free to contact me

Would you mind if I were to come back and clarify any points you have made to help my understanding?

## Appendix13c: Interview schedule for family Carer/friend. Version 2



**The University of Sheffield**

How do people make decisions about using hospice services?

### Interview Schedule: Family Carer/Friend

Your relative/friend felt that you might be willing to talk about your experience of using the hospice services and caring for your relative/friend. I am interested in what or who helped to make the decision to use the hospice care services and what influenced your decisions? I would very much like to hear your own thoughts and experiences about the hospice service. Some people find it useful to talk and reflect on their experiences.

Everything you say will be confidential and will not be discussed with either your relative/ friend or staff.

Before we start it would be useful to have some background information. Would you mind completing the following questions?

1. Can I ask you your age (if you don't mind?)	
2. Gender	
3. How would you describe your marital status (single, divorced, married)	
4. How would you describe your ethnicity?	
5. Would you mind telling me your highest level of educational qualification? (for example, GSCE or O level, A level, degree, professional or occupational qualification)	
6. What was or is your occupation?	
7. Do you have family and friends who live close by?	
8. Do you have children?	
9. Can I ask how old they are?	

Interviewschedulev2rc18-4-12

10. Who would you say provides you with support and help? (Either emotional support or support with physical care)	i.e. friend, neighbour, family relative
11. Would you say you are the main carer for x?	
12. How long has x been with St Luke's?	

I would very much like to hear your own thoughts and experiences about accessing the hospice service. Some people might find it useful to draw a diagram to map out what has influenced decisions, as this can be helpful to picture and reflect upon experiences. I can provide some examples to show what I mean by this. Others prefer simply to talk through their experiences. Let me know if you think it would be helpful to draw out your experiences.

**Theme 1. Perceptions and Expectations:**

**What were your thoughts and feelings about hospice care generally before you ever came into contact with St Luke's?**

**Prompt:** What did you think a hospice might be like? What images did you have of hospice care? What did those images mean to you? How did those images of a hospice influence your thinking about your friend/relative being referred to hospice services/St Luke's?

**Theme 2. Accessing palliative care services:**

Can you tell me about how x came to be referred to the community team/therapies and rehabilitation day unit?

Was there anything in particular that triggered the referral?

Did you have any choice about whether you wanted x to be referred?

Were you involved in the decision to be referred?

**Prompt:**

When did you first come into contact with the St Luke's services (community or therapies and rehabilitation unit)?-possibly through friends, GP referral

Can you remember how you felt about x being referred to the hospice services?

Did you have any concerns or worries about using the service?

**Theme 3. Carer/Relative Support:**

**What did using the hospice services mean to you?**

**Prompt:** Were you able to talk to your relative/carer about using the hospice services/St Luke's? Whose idea was it? How do you think they feel about it? What did you see as the best options for care?

What are your feelings around using the hospice service?

Was anyone able to support you in making the decision? (Relative, health care professional or charity organisation or website) or did anything else help you?

**Theme 4. Identity:**

**Has x being referred to the hospice changed your relationships?**

**Prompt:** Has it changed your relationship with your friend/relative or other family members? How have friends responded?

Are people supportive?

Are you worried by people's reactions? Can you say why?

How do you manage any changes?

**Theme 5. Challenges to information giving (and receiving)**

**Just looking back to when you x first became involved with the hospice services, did you have the opportunity to talk about your feelings and ask questions?**

**Prompt:** Who did you talk to?

Was it useful to talk to someone?

Were you able to ask questions?

Did the information you were given make sense?

**Some people find it difficult to talk about future care, but have you felt able to talk about and ask questions about future care for x?**

Have you heard of the Preferred Priorities of Care document or used this document?

If you used this document did you think it was helpful?

*(Researcher supplies an example of the PPC document)* If you haven't used this document do you think you would find it helpful or not?

Can you say why?

Do you think that planning for care in the future is helpful?

Can you say why (or why not)?

**Theme 6. Dissonance in understandings**

**Just reflecting for a moment, how do your experiences of St Luke's match your expectations of what you thought the service would be like?**

**Prompt:** Would you have preferred another type of service?

Was there anything in particular you thought would be different?

Did you find it easy to understand what staff were saying to you when explaining services and care?

**Finally:**

**After all your experiences what advice would you give someone in the same boat as you when you first used the palliative care team?**

Thank you for your time and sharing your story. Before we finish is there anything that I should try to understand that we haven't covered?

If you think of anything else you would like to add that we haven't thought of today, please feel free to contact me.

Would you mind if I were to come back and clarify any points you have made to help my understanding?

## **Appendix 14: Anonymised copy of e-mail from bereavement counsellor**

The above client informed me that he was aware his wife had made a voice recording when she had participated in a piece of research being undertaken by Fiona Wilson as part of a phd study. He told me that he had requested a copy of the voice recording as he had no other record of his wife's speaking voice and he felt it would be a precious and important memento.

We discussed this at some length, and he said that it didn't matter what she said it was simply the sound of her voice he would love to hear again. He informed me that he had contacted Fiona and that she had contacted the ethics committee and he was awaiting their decision. He was a little distressed at the delay in the decision-making process.

Fiona Wilson approached me soon afterwards, she was unaware that xxx was receiving bereavement counselling but wanted my advice as to the appropriateness and potential impact of xxx receiving a copy of the tape.

Fiona informed me that there were large sections of the tape when xxx spoke lovingly of her family and how wonderful they had been looking after her during her illness, how proud she was of them etc. I felt that this could not pose any harm, or breach of confidentiality as long as reference to any care delivery organisation or individual could be removed from the recording.

Xx was approaching Fiona on a very regular basis and indeed the issue of the recording was causing him some distress. It was decided to provide an edited copy of the recording to xx. This has subsequently been a much appreciated 'gift'.

Bereavement Counsellor

## Appendix15: Truncated sample of patient interview

**Facilitator:**..... **Fiona Wilson**

(General discussion)

I: Can you remember when you were first diagnosed with your condition, your current condition?

P: 2009

I: 2009. 2010?

P: 2009. I've been fighting this 13 years now.

I: Right ok

P: (Laughing)

I: That sort of threw me a little bit.

P: Yeah

I: That's quite a while isn't it?

P: Yes I've had radiotherapy, chemotherapy and 2 operations and it still keeps coming back.

I: Right. Are you able to say what it is?

P: Yeah it's er what they call a ... blank, I've gone blank. Well it's a sarcoma, it's classed as a sarcoma but it's er not cancerous in that it will kill me but it acts like a cancer.

I: Is that the one that attacks different systems?

P: This one is localised er but it's the other ones that have obviously spread but this is localised and it's unfortunately it's wrapped around my sciatic nerve so it's gets interesting sometimes.

I: Painful?

P: Yeah it's changed my life completely. Chemo changed everything 'cos I'm not the same person I was.

I: After having the chemo?

- P: Yeah you don't realise ... nobody realises the impact it has, they really don't. They don't tell you the impact it has either but I suppose it's individual but yeah it's ...
- I: Did you have chemo 2010?
- P: Yes, sorry 2009 I started chemo and it was in January and I had 10 months, every week for 10 months.
- I: And was that quite a gruelling regime?
- P: Yes they were the worst er what is it ...
- I: Dose
- P: Dose yeah and the chemical itself was the worst that you could get so I got quite ill and became ... lost a lot of weight and became quite ill.
- I: Who looked after you then if you were looking after your mum?
- P: I had a partner at the time [edited section]
- I: Ooh
- P: Yeah so that was a pearler, that really did ... and of course I was so ill.
- I: Did she leave because they hadn't said they wouldn't cure, this isn't part of my study at all, but did she leave they hadn't cured you or because they had cured you to a certain degree?
- P: I think because they'd cured me to a certain degree so I think she'd not got an excuse then to ... not that she did look after me 'cos I had to self-inject and do all my own 'cos I'd got a thing in my neck and had to do everything myself so she didn't really help.
- I: Like a CDP line?
- P: Yeah
- I: Did you?
- P: Yeah and so .. and I think ... I paid for things and bought things and got no money left, she'd got more money than me in fact, 'cos I was giving ... obviously paying rent and that 'cos I'm not that kind of guy. Yes it was a trying time (laughing). So I ended up back at my mums, 56 years old and back at my mum's. You couldn't write it could you (laughing)?
- I: Yeah. Perhaps not what you thought [0:05:37] those years.

P: Yeah but life's not turned out as one expected.

I: I don't think it does for anybody (laughing).

P: No. But yeah that's put me off (laughing).

I: I can see why.

P: Yeah, yeah

I: Getting back to here though ...

P: We digress

I: Just to help me if I write 2008 diagnosed, that's right, and then 2010 was chemotherapy.

P: 2009 was chemotherapy.

I: 2009

P: Yeah. I had a great deal of therapy 2010.

I: So 2008 diagnosed, 2009 chemo which was heavy, I'm going to put plus, plus, plus, 10 months and then what did you just say?

P: 2008, I think 2009 I had radiotherapy.

I: Yeah and that shrunk it down.

P: A little yeah

I: A little bit.

P: It came back in 2008, I'm not sure when I had surgery.

I: These post-its have jammed together. So that's kind of the background but during that ...

Distraction - Building Work

P: It's going to on for a while yet.

I: Oh is it?

P: About another 30 seconds (laughing). That's it. [0:07:24] I'm a [occupation].

I: Oh so you know the sounds. So you had chemotherapy in 2009 and that said you were more or less clear and then how did you get from there to coming to 'cos you said you were in [hospice] in 2010. You came before.

P: I came ... between 2012 and 2015. What ... we're in 15 now aren't ...

I: Yeah

P: ...so I think I was here during 2009 when I was having chemo.

I: Oh right. As an outpatient?

P: Yes from [WP] I think for to help me psychologically with the impact the chemo and feeling ill and depressed and everything. To help me that sort of thing.

I: So this big impact of chemo isn't it. So when [WP] said, that's very negative, erm said we're gonna think about er the hospice what did you know about the hospice up until that point. What's your image?

P: All I knew was that people came here to die.

I: Can I write that down?

P: Yes of course.

I: And you can write things if you want to.

P: Er I would just put one word (laughing). One word and it's just death. That's the ... what everybody thinks. I told my friend that I was coming here and they thought I was terminal.

I: Oh did you?

P: Obviously I'm not but ...

I: Before you came to the hospice, any hospice, death?

P: Death.

I: That's it.

P: When you go in you don't come out. That's the general perception and I knew that I wasn't going to die, I knew er I was coming here for different reasons for the complementary therapies to help me work on the pain.

I: So it was pain management as well?

P: Yeah

I: Complementary ... these have glued together in the heat. So erm so how who made that referral then? You were thinking hospice, I'm not going there.

P: The nurses at Macmillan.

I: Specialist nurses. And how did they ... how did they broach it? Was there something ... was there a crisis? Was there something that made them think ...

P: I was ... I was at a very low point during er this winter and er we'd gone as far as we could go with the medicines, they were getting to a point where they were making me doopey and sleeping and I've still got a bike and I want to ride my bike and drive a car obviously so I don't want my licence taking off me so they thought of coming here to try other complementary treatments to see if they could circumvent the pain or change my attitude to the pain sort of thing which is easier said than done. I mean she qualified that by saying that so it's getting round the pain and working out 'cos I've gone from being active to er well I've had to quit work, I can't walk, I can't do stuff like that. I can't walk for far anyway.

I: Was that in 2010 you quit work? No?

P: Er yeah, just before the treatment. I think it was Christmas 2011.

I: Everything happened then.

P: Yeah I were glad to quit because my mates were helping me dress and put my boots on going to work, I were ... you do don't you, I've never been out of work, works since 1982 and I've got a strong work ethic so one of the doctors said it's like a bereavement losing my job and ... this is why the psychological part comes in to er ...

I: Because then you were what, 40 at that point, no ... only about forty something?

P: Three years ago

I: Oh right yes. Yeah. Ok so they suggested the hospice and you told your friends. What was their response then?

P: They thought that I was withholding information like are you sure, are you alright, are you alright? I said yeah, yeah. Well you know what the hospice is don't you, you go in and they don't come out.

I: They said that to you?

P: Yeah. I said no that's not going to happen with me it's er this is ... I haven't got a cancer that will kill me, I've just got one that makes my life bloody hard but I said don't worry, I'm dying, I'm not gonna die, I'm just going for complementary therapy and see what else we can do.

I

## Appendix16: Short extract from research diary

20-2-2014

### **Insecure Sanctuary:**

This is to capture the notion that having arrived at the hospice following experience of abandoned care at the acute sector (and it seems it is the abandonment of care as the acute aspect of the care – so surgery seems straightforward but the caring dimensions of longer stay are absent with a feeling of insecurity and almost abandonment) – I use abandonment as it contrasts to the feeling of significance- which hospice seems to offer, and provides a contrast- so rather than feeling insignificant there is a more of a fear element in accounts and abandonment perhaps captures more of the fear and hurt involved.

It may be that the working hard to live. Insecure sanctuary captures the relief of those who finally meet find they are listened to- so significant, and secure but then find the effort in working hard to live, is supported. Even by meeting other people or patients who are in the same boat. So some describe meeting others in the same boat, chemo buddies or three muskateers and the relief as dying is a lonely activity (could this be a new them?)and then find that their friends begin to die. Often without having the opportunity to attend funerals or be notified. So the sanctuary is precarious. Perhaps therefore part of the working hard to live and getting a terminal status could be supported by more supportive care work. them realise it is life affirming too.

Sanctuary: Listening to transcripts again and trying to code. The codes do not quite make as much sense now or is it that the participant I am listening too, has a different view point. I need to record who is actually bereaved and who is caring and what impact this has. Added new codes around unrealistic certainty- two are sure they have 'booked' beds.

Also how does they know – have they cared for others at the hospice?

I realise I did not ask about spirituality or religious faith but the chaplaincy does come up –even though people indicate they are not religious they do often mention the chaplain, or the chapel. And of course as I waited in therapies I was often sitting with one of the volunteer chaplains. It would be useful to revisit in future interviews. The interview I am listening to commented that he was not 'into all that' but at the same time, it is the hospice chaplain who conducts a relative's service. So maybe some contradictions, but perhaps having or knowing of the spiritual support adds the notion of a sanctuary and how the hospice might be different from other day centre settings?

## Appendix 17: Memo exploring the theme 'insecure sanctuary'

I heard on the radio that sanctum means holy- and perhaps I have inadvertently chosen the right word – sanctuary here. Looking at the online definition below it captures quite a lot of the hospice – an immunity against some of the acute care experiences and lack of integrated care system, a refuge and somewhere private as well as holy. So there seems to be all of these dimensions here, but this also presents a problem as Howarth had noted that hospices are white middle class places and it is unknown whether the sanctuary feel is something that would appeal to other cultures/religions. I am also reflecting that there was display in the reception which used the logo- a place to be myself- and this might fit in with the idea of sanctuary as a private room as well.

### World English Dictionary

**sanctuary** ('sæŋktjʊəri)

— *n* , *pl* -aries

1 a holy place

.

2 a consecrated building or shrine

.

3 *Old Testament*

.

a. the Israelite temple at Jerusalem, esp the holy of holies

b. the tabernacle in which the Ark was enshrined during the wanderings of the Israelites

4 the chancel, or that part of a sacred building surrounding the main altar

.

5 a. a sacred building where fugitives were formerly entitled to immunity from arrest or execution

b. the immunity so afforded

6 a place of refuge; asylum

.

7 a place, protected by law, where animals, esp birds, can live and breed

. without interference

[C14: from Old French *sainctuarie*, from Late Latin *sanctuārium* repository  
*sanctus* holy]

Collins English Dictionary - Complete & Unabridged 10th Edition  
2009 © William Collins Sons & Co. Ltd. 1979, 1986 © HarperCollins  
Publishers 1998, 2000, 2003, 2005, 2006, 2007, 2009  
[Cite This Source](#)

*Etymonline*

## Word Origin & History

### **sanctuary**

c.1340, "building set apart for holy worship," from Anglo-Fr. *sentuarie*, from O.Fr. *sainctuarie*, from L.L. *sanctuarium* "a sacred place, shrine" (especially the Hebrew Holy of Holies; see [sanctum](#)), also "a private room," from L. *sanctus* "holy" (see

The sanctuary offers security in some ways, so this theme was re explored and seemed to capture the precariousness of the sanctuary. So finding a sanctuary captures the relief and support and the essence of the hospice but finding a precarious sanctuary also captures the realisation that the time at the hospice is short lived and they may finish.

07-04-2015 Just discussing memoing with xx. Describing how I came to insecure sanctuary. I say it took awhile to capture the insecurity aspect of this and also how it is temporary. She then quickly retorted temporary refuge. And indeed there is a sense of it being a refuge- fleeing from care, findings some peace. The sanctuary matches some of the Christian elements of the hospice but the notion of refuge- a place to flee to or feel sheltered from pursuit, danger, or trouble and this may actually be a better fit?

# Appendix18: Presentation to hospice management team 4-11-15

Update of study progress

CHOICE AND DECISION-MAKING AT END-OF-LIFE:  
HOW DO PEOPLE MAKE DECISIONS ABOUT USING HOSPICE SERVICES?

---

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2015

What's important to me.  
A Review of Choice in End of Life Care

Choice at end-of-life

*"A core value for palliative care has been to enable people to make choices about their end-of-life care and place of death".* World Health Organization 2011

- The term 'patient choice' is present in all current health policy documents, including those focussing on palliative care.

Decision Aid Tools

No decision about me without me....

"We want the principle of "shared decision-making" to become the norm: no decision about me without me." (DH 2010:13)

End of Life Care Strategy  
Meeting up with us in a state of mind (19)

Essential care planning and advance care preferences in the lasting strategy (2010:13)

But what is meant by choice?

- But what informs choice in palliative care?
- How are choices communicated and understood?
- How are decisions made?
- Are risks associated with choice?
- And what sort of choice does hospice care offer?

### Study Aims:

- **Objective:**
  - To explore decision-making in the transition to Hospice Care
- **Aims:**
  - How do those facing end-of-life make sense of choices?
  - What beliefs and understandings inform palliative care preferences?
  - What is the impact of ethnicity, age, and gender on understandings around choice and hospice care?
  - How do service providers (nursing staff, medical staff, doctors, managers) provide and support choices for individual patients?
  - How are decisions negotiated between service user and service provider?
  - How useful are end-of-life tools such as the Preferred Priorities of Care document in facilitating decision-making?

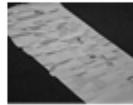
### Interviews to focus on following based on literature review and SCGT:

- Perceptions and expectations of hospice services
- Access and referral to palliative care services
- Care/Relative Support
- Impact on Identity and self
- Information giving/receiving
- Understandings of palliative care
- Preferred Priorities of Care Document and future care

### Design: Case study of triad Interviews framed by Social Constructivist Grounded Theory (Chamaz 2006)



### PICTOR

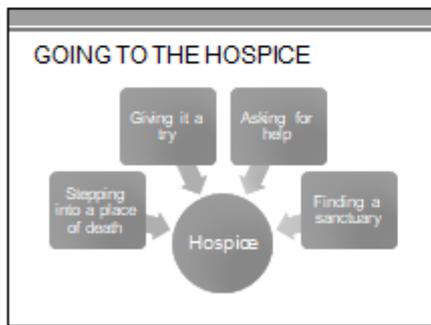
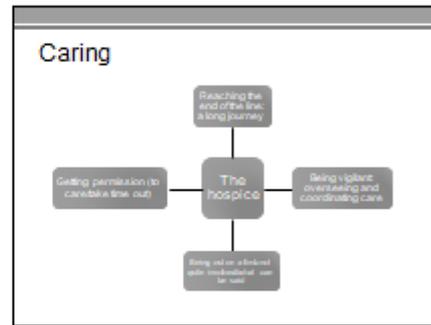
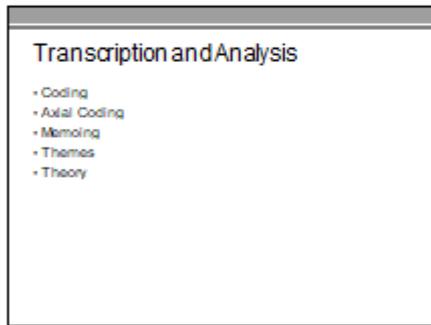
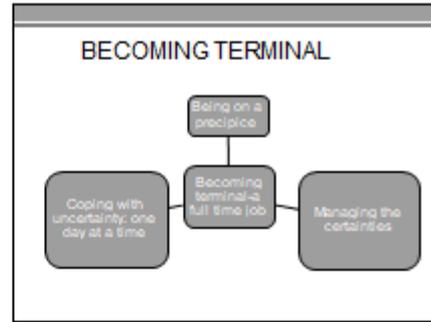
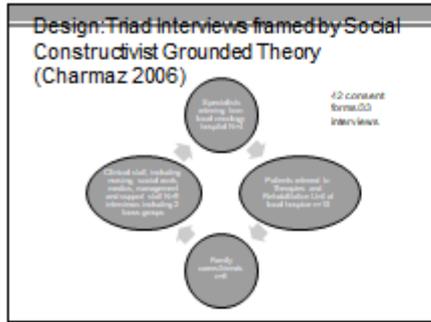


### Ethics

- Specialist palliative care nursing staff to assess and offer a study pack and invitation to participate to all patients referred for assessment over a 6 month period to the Community Team or Therapies and Rehabilitation Unit
  - Patients to be approached only if considered:
    - Able to discuss their experience around transition to palliative care, without undue distress
    - Able to understand and engage in the study
    - And are not experiencing such severely debilitating symptoms that the study and interview would be onerous.
  - Patients to consent. Identified member of staff involved in their care being approached for interview
  - Patients to consent. Identified family member/carer/ward being approached for interview
- Ethical review number: 12/14/2011  
• PRC reference: 12/14/2011  
• Project number: 04/1028  
• IRAS project ID: 8838

### Data Collection

- Having had the support of the advisory group to refine and practice using PICTOR and the semi-structured interview schedule, data collection was systematically planned over a 6 month period from January to June 2013
- Outcome:**
  - Data collection commenced June 2013
  - 40 study packs distributed to the community nurses including those in trials (at great cost).
  - No replies
  - 20 packs distributed to Therapies and Rehabilitation Unit
  - 15 interviews with Patients over 2 years
  - 10 packs distributed to Carers Support Group
  - 8 interviews with carers
  - 12 interviews with staff from the hospice and W/H including 2 focus groups. 2 interviews and 1 focus group were unable to be recorded.
  - Ethics re visited for W/H including IRAS Clinical Trials Committee etc.
  - Data collection complete by December 2014



File	Author	Size	Created	Modified	Accessed	Download	View	Share
01-01-2015		10	01 Aug 2015 14:00		01 Aug 2015 14:00			
02-01-2015		10	02 Aug 2015 14:00		02 Aug 2015 14:00			
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28-01-2015		10	28 Aug 2015 14:00		28 Aug 2015 14:00			
29-01-2015		10	29 Aug 2015 14:00		29 Aug 2015 14:00			
30-01-2015		10	30 Aug 2015 14:00		30 Aug 2015 14:00			
31-01-2015		10	31 Aug 2015 14:00		31 Aug 2015 14:00			

## And finally

- The study has been informed and supported by the staff and patients at St Luke's Hospice
- I would particularly like to thank the management team, and Nurses in the Therapies and Rehabilitation Unit who have worked really hard to support the study

## Memoing for example:

- Providing a Plan for
- Following procedure and protocol with intention
- Outcomes
- There is a tension between formalising decisions and following procedures whilst relying on one's own intuition. The latter is more around looking for ways to start conversations and develop a coaching approach as well as recognising that documentation and protocol are sometimes unclear. Documentation around decisions also presents dilemmas or at least not address the individual so that in some ways the use of protocols and forms become part of the ritual of becoming a palliative care patient.
- Some patients are regarded as not ready to make decisions about care needs, and there is a belief that body changes will override plans. From that in some interviews the theme of supporting a patient's journey is common (not the 2 words and some implications for staff) using documentation and following procedure may impede the development of a coaching relationship particularly in initial interactions as the introduction of care needs is too sudden and too hard. However, whilst protocols, GPC, PFC and so forth, are given to patients, at the same time, staff recognised that documentation offers a means of finding out preferences and starting discussions. In some ways their usage is both a prop and an obstacle to care planning but there is some organisational demand to use various tools - almost a part of a ritual.

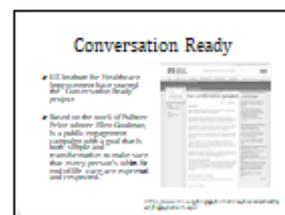
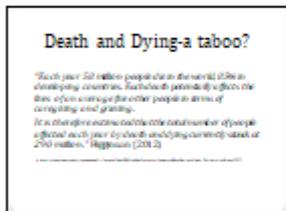
## Contact details

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 0114 225 2247

## Outputs to date:

- *Being on the outside: The experience of family carers of patients attending a hospice day unit. Abstract submitted to Palliative Care Conference 2015 (decision pending - fingers crossed)*
- *Going to the hospice: a qualitative study exploring patient perceptions of choice around accessing a hospice day unit-submitted to JAN (decision pending-fingers crossed)*
- *Death Cafe: Dying Awareness Week 2015 SHU*
- *Wilson, F, Ingleton, C, Gull, M., Gardiner, C. (2014) Perceived Risks in Decision Making. Poster Presentation, Proceedings of the 10<sup>th</sup> Palliative Care Congress 2014, Harrogate.*
- *Wilson, F, Ingleton, C, Gull, M., Gardiner, C. (2014) Autonomy and Choice in Palliative Care- time for a new model? Journal of Advanced Nursing, 70 (5) 826-828 DOI: 10.1111/jan.12267*
- *Wilson, F, Gull, M & Ingleton, C. (2013) Perceived risks around choice and decision making at end-of-life: a literature review. Palliative Medicine, 27 (1) 38-53 , doi: 10.1177/0269216311424632*

# Appendix 19: Presentation to Sheffield Hallam Learning & Teaching Conference 2015





### The Good

- Core consensus around issues: good and bad
- The play yourself
- The value
- To share with the medical director of St Luke's hospital
- Goal to discuss a video soon
- The video was low of reflection
- The choice was

*video film*  
 • *single issue and think on behalf of most conditions with limited air time*  
 • *with representation for representing each condition and assigned roles. It really did help us to all share our own views on the pros and cons of other conditions. We were pleased to have a group of about 4 nursing students.*



### And the bad

- Need more on dealing with suicide
- Child development
- More advertising
- More multi-faith and faith perspectives
- More discussion on practical aspects

Actually, it sounds like people wanted more....?

### What now?

- Further evaluation - ethics approval of our further qualitative interviews with attendees
- Develop an End-of-Life and Palliative Care toolkit of which communications about death and dying could be an ongoing feature
- Develop further and social media
- Partnership working
- Explore drama and education leading students to writing, performing and reading other
- Try to come more, encourage online responses to delivery
- Do it next year?

- [2014/15/16 End \(2016\) The Position of Adults at the End of Life](#), 4 Dec 2016, [http://www.bmj.com/](#) 4
- [2012/13/14 Inter \(2013\) Circumstances of death and dying in 100,000 in England, 11 Dec](#), [http://www.bmj.com/](#) 4
- [2012/13/14 Inter \(2013\) Circumstances of death and dying in 100,000 in England, 11 Dec](#), [http://www.bmj.com/](#) 4
- [2012/13/14 Inter \(2013\) Circumstances of death and dying in 100,000 in England, 11 Dec](#), [http://www.bmj.com/](#) 4

### Some graphs

- How relevant was the death cafe to your learning?
- How relevant was the death cafe to your personal development?

### Thank you for listening

- A big thank you to our partners and team at the Sheffield St Luke's Hospice
- Thank you also to the End of Life and Palliative Care Team including Anne (Joana), Malvina, Ruth, Kate, Mike, Roy and SUE, Audrey, Kirsty, Jane, Tessa, Sabine, Maria, Kath, Steve, among many
- Big thanks to Ashley Barnes and the Drama Students as well as Laura Wade
- Also thanks to Maria and Spencer and Warran for PDS cake

# Appendix 20: Cancer and Palliative Care Showcase Event.



## Cancer and Palliative Care Showcase Event

Wednesday 18th May 2016

10.00am - 1.00pm

Collegiate Crescent Campus, Sheffield Hallam University (room to be confirmed)

### Programme

9.30 - 10.00	Registration and refreshments	
10.00 - 10.05	Welcome	Professor Karen Collins, Chair of the Faculty Cancer Interest Group
10.05 - 10.15	A Faculty perspective on cancer and palliative care	Professor Karen Bryan, Pro-Vice Chancellor, Faculty of Health and Wellbeing, Sheffield Hallam University
10.15 - 10.40	Keynote address - Changing priorities in palliative care research	Professor Bill Noble, Honorary Professor of Community Palliative Care, Executive Medical Director of Marie Curie and Honorary Consultant Physician at the Sheffield Macmillan Unit of Palliative Care and the Northern General Hospital
10.40 - 11.10	Working together to improve cancer care, palliative care and end of life care in Sheffield	Marianne Hargreaves & Anthony Gore, Strategic Leads for End of Life Care, Sheffield Clinical Commissioning Group, and Siobhan Horsley, Public Health Improvement Lead for Cancer, Sheffield City Council
11.10 - 11.20	Predicting the responses of anti-tumour agents to therapy	Neil Cross, Biomedical Research Centre, Faculty of Health and Wellbeing, Sheffield Hallam University
11.20 - 11.30	Increasing societal awareness of death and dying	Fiona Wilson and Barbara Beard, Faculty of Health and Wellbeing, Sheffield Hallam University
11.30 - 11.45	Break and opportunity to view poster presentations	
11.45 - 12.00	Time for change - walking the path together	Sandra Clarkson, Macmillan Development Manager, Macmillan Cancer Support
12.00 - 12.15	Supporting patients physical and psychological wellbeing through physical activity: making it happen	Dr Helen Crank, Sheffield Hallam University
12.15 - 12.30	Priorities for Palliative Care in the Acute Hospital Setting	Rev. Dr Mark Cobb, Clinical Director of Therapeutics & Palliative Care, Sheffield Teaching Hospitals NHS Foundation Trust
12.30 - 12.45	Facilitating online conversations in end of life care - a Sheffield Hallam University open course in partnership with St Luke's hospice	Sue Willis, Faculty of Health and Wellbeing, Sheffield Hallam University
12.45 - 13.00	Round up and close	Dr Julie Skilbeck, Chair of the Palliative and End of Life Support Care Interest Group