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**Finding a voice at the end of life: exploring  
preferred place of death in a hospice context.**

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PhD thesis

October, 2016

Keele University

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## SUBMISSION OF THESIS FOR A RESEARCH DEGREE

### Part I. DECLARATION by the candidate for a research degree. To be bound in the thesis

Degree for which thesis being submitted                      PhD

Title of thesis    Finding a voice at the end of life: preferred place of death in a hospice context

**This thesis contains confidential information and is subject to the protocol set down for the submission and examination of such a thesis. NO**

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- (a) The thesis being submitted for examination is my own account of my own research
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- (c) The data and results presented are the genuine data and results actually obtained by me during the conduct of the research
- (d) Where I have drawn on the work, ideas and results of others this has been appropriately acknowledged in the thesis
- (e) Where any collaboration has taken place with one or more other researchers, I have included within an 'Acknowledgments' section in the thesis a clear statement of their contributions, in line with the relevant statement in the Code of Practice (see Note overleaf).
- (f) The greater portion of the work described in the thesis has been undertaken subsequent to my registration for the higher degree for which I am submitting for examination
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## **Abstract**

This study explored the views of patients, carers and staff within one UK hospice on talking about preferred place of death (PPD). The UK Government's End of Life Care Strategy (EOLC, 2008) states that patients' PPD should be identified, documented and reviewed; yet the hospice in this study did not systematically record such information. It was, therefore, important to ask questions about patient, carer and staff views on PPD as this had not yet been explored. Hence the aims of this exploratory study were to:

- Explore key considerations about PPD from the perspectives of hospice patients, carers and staff
- Generate theory about the participants' experience of PPD

The methodology of constructivist grounded theory enabled a substantive theory to be generated which offered an interpretative explanation of the participants' concerns regarding PPD. Data collection methods of focus groups amongst hospice staff, and semi-structured interviews with hospice patients and carers, captured the views of a cross-section of people within the hospice context.

The grounded theory demonstrated that recording the patient's PPD is a means of 'Enabling the Patient Voice to be Heard'. The ways in which the grounded theory impacts the end of life care landscape were explored including questions around contemporary societal discourses on death; current end of life planning; communication issues at the end of life; health service provision and the roles of healthcare professionals, patients and carers.

A reflexive account of the research process and the limitations of the study are also presented. The unique contribution of the study is stated and recommendations for further work are suggested.

**Keywords:** palliative care; end of life care; preferred place of death; hospice; qualitative; user and carer perspectives; reflexivity; ethics; constructivist grounded theory.

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To God be the glory.

## Preamble

Parts of this thesis draw on material from four of my publications. All of the published material has been adapted and is included with kind permission from the various publishers, which is documented in Appendix 8.

The location of the adapted published material within the thesis is detailed below.

**Chapter One Background and Context: 1.4 The Evolution of This Study** uses material from Walker, S., Read, S. and Priest, H., 2011. Identifying, documenting and reviewing preferred place of death: an audit of one UK hospice. *International Journal of Palliative Nursing*, 17(11), pp.1-7.

**Chapter Five Methods and Procedures** uses material from Walker, S. and Read, S. 2011. Accessing vulnerable research populations: an experience with gatekeepers of ethical approval. *International Journal of Palliative Nursing*. 17(1), pp. 14-18.

**Chapter Six Methods of Data Analysis** draws on material from Walker, S. Read, S. and Priest, H. 2013b. A researcher's experience of focused coding in grounded theory: what makes the final cut? *Qualitative Methods in Psychology Bulletin*. 15(Spring), pp. 23-32.

**Chapter 11 A Reflexive Account of the Research Process and Limitations of the Study** uses material from Walker, S., Read, S. and Priest, H. 2013a. Use of reflexivity in a mixed-methods study. *Nurse Researcher* 20(3), pp.38-43.

## **Chapter One           Background and Context**

### **1.1     Introduction**

This chapter provides the background and context for this research study which explored the views of patients and carers within one UK hospice on talking about preferred place of death (PPD).

The topic of talking about death is introduced and an explanation of why this was pertinent to the participants in this study is given. The term palliative care is defined and the development of the modern hospice movement is briefly charted. As a means of identifying how the hospice within this study relates to palliative care in the wider context, current global and national palliative care provision is outlined. An overview of services offered by the hospice within this study is provided.

The subject of preferred place of death is introduced and its role in anticipatory planning for end of life care is explained. Another term which is also found in the end of life care literature “preferred place of **care**” is introduced and its relationship to preferred place of death is briefly outlined.

An account of how this study came about is presented. This describes my transition from practitioner as hospice chaplain to PhD student and the preliminary scoping work I carried out to support the research proposal.

### **1.2     The Contextual Backcloth of Palliative Care**

#### **1.2.1 Talking About Death**

Woody Allen is famously quoted as saying that he was not afraid to die: he just

didn't want to be there when it happened. Whilst this may be an authentic reflection on death and dying, it remains a rather abstract one, giving the impression that, for now at least, the matter is of no immediate concern. This study, however, was concerned with people talking about end of life at a time when concerns about death were immediate and pressing, because it was situated within the context of one UK hospice which provided palliative care to people with life-limiting or terminal illnesses. In particular, this study involved people associated with this UK hospice who were approaching the end of their lives and with those who cared for them either in a professional capacity or as a relative or close friend. Through interviews and focus groups, issues around talking about end of life care from the perspective of hospice patients and their carers were explored and analysed. Hence, the backcloth against which the conversations about end of life took place was the palliative care context.

### **1.2.2 Defining Palliative Care**

Palliative care has been defined by The World Health Organisation (WHO) as:

“an approach that improves the quality of life of individuals 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” (WHO, 2002).

Building on this definition, the UK National Institute for Clinical Excellence (NICE, 2004) purports that the goal of palliative care is the achievement of the best quality of life for patients and their families. With this in mind, palliative care aims to:



- Affirm life and regard dying as a normal process
- Provide relief from pain and other distressing symptoms
- Integrate the psychological and spiritual aspects of patient care
- Offer support to help patients live as actively as possible until death
- Offer support to help the family cope during the patient's illness
- Offer support to help the family in their own bereavement. (NICE, 2004).

Palliative care, then, is the holistic and total care of someone who is approaching the end of life, combined with offering care to the patient's family and carers. It aims to maintain and improve the quality of the life of the patient, to offer support during the course of the illness and to offer support to the family and carers following the death of the patient. Such an holistic approach is the very opposite of a reductionist view which would tend to see palliative care as symptom control alone. Whilst good symptom control is vital, within a palliative care approach, other nondrug aspects of care are also considered to be important to the patient and their family. Such elements include:

- Self-help and education
- User involvement
- Information giving
- Psychological support
- Social support
- Rehabilitation
- [Complementary therapies](#)
- Spiritual support
- End-of-life and bereavement care. (NICE, 2004)

### **1.2.3 The Modern Hospice Movement and Palliative Care**

The contemporary concept of palliative care which has been outlined, has its origins in the modern hospice movement. The first modern hospice, St Christopher's in London, was founded in 1967 by Dame Cicely Saunders, where the holistic and total care approach for people with life-threatening conditions was developed. Since then, hospices have become leading providers of such care. From the outset, there has always been variety in the expression of palliative care whereby ideas developed at St Christopher's have germinated differently within different care contexts. For example in the UK, within a decade of the founding of St Christopher's, it was accepted that the principles of hospice care could be practised in many settings; not just in specialist inpatient units, but also in home care and day care services. Additionally, in some areas of the UK, hospital palliative care units and support teams were established which served to spread this holistic and total care approach towards dying into the UK acute medical arena. Acute medical hospitals' area of expertise is the medical management of diseases with the effective discharge of patients back into the community. However, because people sometimes die in such settings, the palliative care approach has much to offer the acute hospital.

The development of palliative care has not been confined to the UK: it is a phenomenon which is seen to a greater or lesser extent across the globe. As a means of advocating for and promoting palliative care in the global context, networks such as the Worldwide Palliative Care Alliance (WWPCA), the International Association for Hospice and Palliative Care and the International Observatory on End of Life Care were developed specifically for this purpose.

### **1.2.4 The Global Context of Palliative Care**

In 2014, the Worldwide Palliative Care Alliance (WWPCA) and the World Health Organisation (WHO) collaborated to produce a Global Atlas of Palliative Care at the End of Life (WWPCA &

WHO, 2014). According to this atlas, it was estimated that across the globe, over 20 million people require palliative care at the end of life every year.

Whilst the number of patients receiving specialised palliative care worldwide is unknown, it is estimated that the numbers of patients who die while receiving palliative care services is in the region of three million, or about 14% of those across the globe who are in need of palliative care at the end of life (Lynch, Connor and Clark, 2013).

In 2011, 136 of the world's 234 countries (58%) had one or more hospice palliative care services established, but a significant number of countries had no hospice-palliative care provision and global development may best be described as 'patchy'. Approximately 16,000 service units were identified worldwide with enormous variety regarding the ratio of palliative care unit to population served. Globally, this ranged from 1: 1000 in Niue, an island country in the South Pacific Ocean, to 1: 90 million in Pakistan.

In some countries there is no government support whatsoever for palliative care. In others, such as Romania and Zimbabwe, charitable palliative care services have developed, whilst in the UK there is a partnership model whereby up to 40% of palliative care funding comes from the government with charities providing the rest of the finance required. In the worldwide context palliative care provision is diverse and evolving. Impetus has been given to its continuing evolution by the philosophical view that palliative care is a human right (Brennan, 2007) supported by international declarations such as the International Human Right to Health from the International Covenant on Economic, Social and Cultural Rights (ICESCR) Article 12.1 (UN,1966), which calls for the "right of everyone to the enjoyment of the highest attainable standard of physical and mental health". In addition, many

international organisations and bodies have called for the provision of palliative care as an essential component of healthcare, including the WHO, the Senate of Canada (2000), the European Committee of Ministers (2003), the European School of Oncology (Ahmedzai et al., 2004), the WPCA (2005), and Human Rights Watch (Dekker et al., 2012).

### **1.2.5 The UK Context of Palliative Care**

Since the opening of St Christopher's Hospice in 1967, palliative care provision in the UK has grown in various ways. In the early 1970s development came mainly from the independent, charitable sector. During this period, the National Society for Cancer Relief (now known as Macmillan Cancer Support) began a programme whereby capital grants were given to units built within National Health Service (NHS) hospital grounds, with health authorities taking over some responsibility for their running costs. Hence a type of partnership model came into existence. Nowadays different kinds of partnership models exist whereby charities and the NHS share funding responsibilities and some palliative care is provided solely by the NHS. Non-NHS hospices provide 80% of the beds in the UK for those receiving end of life care, with most of their income deriving from charitable donations and legacies. The different categories of palliative care currently available in the UK are as follows:

**Independent or Voluntary Hospices** - these units are registered charities financed mainly by charitable income. They have firm links in policy and practice with the National Health Service but receive only partial funding from local NHS commissioning groups. In addition to inpatient care most hospices provide home care, day services and bereavement support. Some buildings are purpose built, while others may have been established in a converted building. Units range in size from two to 63 beds.

**Marie Curie Centres** are administered by the national charity, Marie Curie Cancer Care. In addition to 11 homes there are 6000 part-time Marie Curie Nurses who nurse patients in their own homes.

**Sue Ryder Homes** administered by the national charity, the Sue Ryder Foundation, provide palliative care for patients with cancer in all of their homes, and several have visiting nurses who attend patients in their own homes, both before admission and after returning home.

**Macmillan Cancer Care Units.** Macmillan Cancer Relief has funded and built many inpatient and day patient units, mostly on hospital sites and now being funded and operated by the National Health Service. Macmillan has also funded, or part funded, several units operated by the voluntary sector.

**Palliative Care Wards/Units in NHS Hospitals.** Some hospitals have units or wards where patients benefit from the principles and practice of hospice care. The cost of palliative care provision varies from 100% funding by the National Health Service to almost 100% funding by charities, but the service is always free to patients. Palliative care provision for adults in the UK currently includes

- 223 hospice and palliative care inpatient units
- 3,200 hospice and palliative care beds
- 291 home care services
- 129 Hospice at Home services
- 275 day care centres
- 346 hospital support services, (Help the Hospices, 2012).

Those involved in delivering palliative care may extend beyond those listed to include informal carers (such as family, friends, and neighbours); privately provided nurses or carers

assisting the family; voluntary organisations and patient groups providing information and support and primary care providers including General Practitioners and district nurses.

Hospices receive an average of 34% of their funding from the government, with around £1.6 million being expended daily on the provision of hospice care. GPs and hospital palliative care teams are funded by the government under local service level agreements. It is estimated that between 355,000 and 457,000 patients need palliative care every year in the UK (Help the Hospice, 2012).

### **1.2.6 The Local Context: The Hospice in This Study**

The research site for this study is located within a substantial conurbation in the UK midlands. Provision comprises a hospital palliative care team and a hospice, both of which work together with primary care services. The hospital palliative care service is available for all patients with palliative care needs and provides advice and support to patients and staff. Using a multidisciplinary approach, advice is provided about pain and symptom control and information, advice and direction about advanced life limiting diseases, in addition to information about services which can provide social or financial help. This team sometimes refers patients to the local hospice, a nursing home or community hospital. It also offers advice about care of patients at the end of life to hospital staff. The hospice provides comprehensive specialist palliative care to adults with progressive advanced disease and limited life expectancy. There is a 28 bed inpatient unit to which patients may be admitted for symptom control, respite care or end of life care. The average length of stay on the inpatient unit is 12 days. A Day Therapy Unit offers patients access to a range of different therapies and professionals including physiotherapy, complementary therapies, diversional therapies, chaplaincy support, psychological support and social work.

A community palliative care nurse specialist team provides advice and support to patients and their families, and assessment of patients who may require admission to the hospice. The community team may refer patients for a hospice outpatient appointment in order to access a palliative care doctor, psychologist, chaplain or nurse specialist. They also liaise with local GPs regarding patient care in the community. A Hospice at Home service is available for people in the last few days of their life who wish to stay at home. This service provides hands on nursing care for patients and support and advice for families at this time.

Additionally, the hospice provides a 24/7 advice line, staffed by specialist nurses which offers support and advice to patients, carers and other health care professionals. There is also a bereavement service which offers support to relatives, partners and close friends of patients for up to two years after the death of the associated patient.

### **1.3 Preferred Place of Death**

In recent years, choosing a place for one's death has come to be considered as part of good end of life care (DH, 2008) and the phrase 'preferred place of death' (PPD) has come into usage within palliative care. The UK End of Life Care Strategy (DH, 2008) promotes supporting people to articulate their place of choice for death. The Strategy states that all people approaching the end of life should have their needs assessed and their wishes and preferences discussed and recorded in a care plan. This includes setting out preferences about how they are cared for and where they would wish to die. These preferences should be subject to review by the multidisciplinary team, the patient and carers as and when a person's condition or wishes change (DH, 2008). Over the last 10 years, therefore, one of the key themes of public policy in palliative care has been achievement of choice in place of

death (Oxenham et al., 2013). This is in accordance with the UK government approach to healthcare which aims to provide a personalised experience for patients.

In order to provide a personalised experience, it would be important to enable patients to make credible, informed choices regarding the services they use. Such an approach is part of the discourse that endorses choice and control as an integral part of having "a good death".

In addition to factors such as having control over pain relief, to be afforded dignity and privacy; having control over access to information and expertise of all kinds including spiritual and emotional support, having control over where death occurs is seen as an important principle (Smith, 2000, Age Concern, 1999).

In reality, the extent to which patient control over place of death can actually be achieved is limited due to factors such as the availability of different locations for death at specific points in time. Nevertheless, in order to determine whether or not existing service provision meets the needs of palliative patients, it is important to understand what they desire in terms of care at the end of their life, including where they want to die. Therefore discussion about PPD can facilitate anticipatory care planning and service provision.

Another key term in the end of life care literature is 'Preferred Place of Care' (PPC). For some, this denotes the stated preferred place of death of someone who is chronically ill (Barrie, Campbell and Ross, 2010) and is therefore used interchangeably with PPD. It may also mean the place where the patient wishes to receive care for the duration of their illness, but not necessarily for their death. For example, patients may express a desire to be at home for as long as possible, but wish to be admitted to the hospice as death approaches or if symptoms or circumstances change.



For example, a Sue Ryder survey that asked people to differentiate between where they wanted to be in the last year, weeks and days of life clearly showed that the closer they were to death, fewer people want to be at home, and more people want to be in a hospice (Sue Ryder 2013). The proportion of people opting for hospice care rose from 4%, to 17% to 28% in the final year, weeks and days before death respectively. The proportion of people opting for dying at home fell from 91% to 75% to 63% over the same time frame. This suggests that either people's priorities change over the course of their end of life journey, or alternatively, that their understanding of where these might be best catered for changes.

Interestingly, a planning tool developed in order to facilitate discussions around end of life care wishes and preferences and to enable communication of care planning and decisions across care contexts was entitled The Preferred Priorities for **Care** Document (NHS, 2007). In the pre-amble this document states that it is a place *to write down preferences and priorities for care at the end of your life.*

However, for some palliative care practitioners it is important that PPD and PPC are clearly distinguished. Oxenham et al., (2013) found that 'preferred place of death' needed to be discussed with patients and families rather than 'preferred place of care' as place of death discussions enabled clearer plans to be formed and implemented when patients deteriorated.

The notion that PPD is an important tool in enhancing patient choice is not without critique. One consideration regarding ascertaining the patient's PPD is consent. Horne (2010) points to the importance of PPD or PPC discussions being non-compulsory and recognises that discussing death and dying can negatively impact terminally ill patients' ability to cope, which has the potential to cause suffering for some people. Borgstrom (2015) is critical of choice

as a conceptual framework for end of life care planning, doubting its efficacy in enabling service development and provision and doubting the reality of choice for many palliative patients.

Little is known of the views on PPD of palliative patients themselves, as the research base on patients' views on end of life care planning is slim (Clark, 2003). This is partly because the views of carers and healthy people tend to be used when defining a good death, as most people who are dying do not take part in research. It could be that asking an ill population as opposed to a healthy one about end of life preferences would focus on symptom management and security rather than on whether they had been able to access different settings for death (Sue Ryder, 2013). Therefore it would be a useful addition to the debate on PPD if the views of palliative care patients who are approaching the end of their lives were sought.

#### **1.4 The Evolution of This Study**

The idea for this study arose out of my former career as a hospice chaplain. The work of a hospice chaplain is to provide and facilitate spiritual care for patients, relatives and staff. Spiritual care supports the unique spiritual journey of each person, enabling them to explore questions of meaning and purpose and the essence of what it means to be human (Kearney, 1990). It is an approach to care which includes cognitive, emotional and behavioural components (Argyle, 2000) and may or may not include religious care (Cobb, 2003).

Spiritual care is a broad concept and making provision for it often means that the hospice chaplain becomes involved with a wide range of issues which are of importance to people.

For example, in addition to conversing with patients on the in-patient unit and providing a daily service of Christian worship, I organised the weddings of several patients; presided at the funerals of two members of staff; signposted a member of staff as to how to write their will; organised a candle-lit dinner for a patient and her husband; helped a family celebrate Christmas in the middle of July; liaised with prison staff to enable an in-mate to visit their relative at the hospice; taught on spirituality courses in the education department; provided day to day support to hospice staff; organised one last shopping trip for an in-patient and accompanied countless patients as they died. All such work was delivered by working closely with other members of the hospice multi-disciplinary team. This research study does not deal directly with matters of spiritual care but nevertheless the idea for it grew from information discovered during the planning of the hospice chapel memorial service.

As part of my professional practice, once a month I led a memorial service in the hospice chapel to commemorate all the patients of the hospice who had died during that month. At this service, the name of every deceased person who had been associated with the hospice as an in-patient, Day Hospice patient or community patient was read out. These names were readily available as the hospice medical records department routinely collated a monthly list of deceased patients which was sent to the chaplaincy department. As this list was originally generated for the purpose of record keeping, in addition to the name of each patient and the date of their death, the place of death was also recorded.

I noticed that many hospice patients did not die in the hospice and that a high proportion of them died in the local hospital. In 2007, in an average month, two thirds of patients did not die at the hospice: of this two thirds, some died at home, a few died in nursing homes and around half died in the local hospital. I found myself wondering about the circumstances and

decisions which had led to the patients dying in these different locations. The monthly deceased list could not answer these questions as it recorded *where* the patients died but not *why* they died in their various locations.

The fact that so many hospice patients died in the local hospital (around one third) was particularly intriguing. Over a period of several years, I had listened to many patients who were quite sure that, at this stage of their lives, the local hospital was not their first choice as a location for future care. Although some spoke highly of the treatment they had received during periods of acute illness and at a stage when active treatment was still considered appropriate, many people considered the hospice to be a more appropriate setting for them to receive palliative care. Some patients were quite hostile to the idea of returning to the local hospital to receive further treatment or care. Questions arose in my mind as to whether dying in the hospital had been an active choice by the patient or whether other factors had led to this outcome.

Anecdotally, I was aware that many hospice patients died in the local Accident and Emergency Department (A&E), having arrived via emergency ambulance, leading to the assumption that this was the default course of action for hospice patients becoming unwell at home.

About the same time as these thoughts around patient choice and planning for end of life care were coalescing, I attended a conference organised by *Help the Hospices* which afforded the opportunity to become acquainted with other current national and international hospice practice and research. A number of presentations were concerned with planning for end of life care and used the term 'Preferred Place of Death' (PPD). Although

new to me, this term seemed to fit with the recent questions arising from the monthly memorial list around patient choice and forward planning. On returning from the conference, I approached the head of the hospice education department to discuss my observations and float the possibility of writing a paper on the death location of this hospice's patients and how this related to the notion of PPD. The head of education suggested that this idea might be much more than a single paper and could be developed into a PhD research proposal. Therefore two potential supervisors from the local university were contacted and the observations and questions that had arisen from the memorial service were developed into the research proposal for this study. By the time of the commencement of the study, however, I no longer worked as a chaplain at the hospice.

As a piece of preliminary work to support the research proposal, I carried out a retrospective audit of patient case notes (Walker, Read and Priest, 2011). In order to discover the extent to which patients' PPD was identified, documented and reviewed at the hospice, the audit examined 150 case notes of deceased former hospice patients who died in January 2008 (n=50), January 2009 (n=50) and January 2010 (n=50).

The audit findings showed that the sample of 150 patients of this hospice died in a variety of settings, namely the hospice, the acute hospital, the patient's home and nursing homes, with around one third (40) dying in the hospice, one third (40) in the acute hospital and one third (53) at home with a few patients dying in nursing homes.

The preferred place of death was documented in a small number of case notes, that is, 28 (19%). 122 patients (81%) did not have their PPD documented. Of the 28 patients who recorded their preferred place of death, 24 actually died in the location of their choosing.

The fact that a high proportion of patients whose preferences were recorded did actually die in their stated location illustrates that recording PPD may help people to die in their place of choice. The evidence from one year was particularly compelling: in January 2009, 100% of patients whose PPD was recorded died where they wished to.

There were only a few (16) recorded conversations about preferred place of death and the professionals conversing with patients on this matter and recording such conversations were, largely, hospice community nurses (13), with a small number of hospice doctors (three). With regard to reviewing patients' preferred place of death, this happened infrequently (six) and within those parameters one third of patients (two) chose a new preferred place of death.

Thus, the audit provided empirical data about contemporary culture and practices around PPD at the hospice, but did not offer explanations about the phenomena observed. It raised questions around why patients recorded or did not record their PPD; why patients talked to particular members of staff and the effect of patients' potentially changing wishes on the notion of PPD. Such questions could not be answered by an audit but through an in-depth exploratory approach which investigated the reasons for decision making regarding PPD from the perspectives of those engaged in this activity. In these ways the audit supported the case for this research study which explored decision making regarding PPD in rich qualitative detail.

## **1.5 Summary**

This chapter has introduced this research study by presenting the contextual backcloth of palliative care in the global, national and local contexts. The aetiology of this study has been described. Chapter two will describe the initial literature review.

## **Chapter Two: Initial Literature Review and Findings**

### **2.1 Introduction**

This chapter describes why and how the initial literature was undertaken at the outset of this study and how the knowledge arising from it informed the research. The different views held on the use of the literature review in grounded theory are presented and the approach taken in this study regarding the use of the literature is described. The initial literature review is then presented and discussed.

### **2.2 Use of the Literature in Grounded Theory**

In most approaches to research, the literature review is undertaken at an early stage, before the research project gets underway and often as an integral part of the research proposal. It is argued that this serves to provide the background of current knowledge on a certain topic and to highlight the significance of the study which is about to begin. Priest and Roberts (2010) suggest that one of the main purposes of the literature review is to make a convincing argument for the research by identifying a gap in the current knowledge which the research hopes to fill. Other reasons cited for carrying out a literature review at the commencement of a study include: to acknowledge those who have worked in this area; to avoid duplicating other people's work and to assist in defining the research question and to place this research in the context of other studies (Holloway and Wheeler, 2007).

This study used grounded theory and within this research methodology the use of the literature review has been much debated. In grounded theory it is important that the study data retain priority for theory generation rather than the current literature directing the focus towards particular issues (Holloway and Wheeler, 2007). A major reason for this is that grounded theory does not begin with preconceived assumptions about a research topic; it



takes an inductive approach whereby the eventual theory is derived from the study of the phenomenon it represents, rather than beginning with a theory or hypothesis which is then tested.

Therefore, grounded theorists have debated whether a literature review should be employed at the beginning of a study at all and if so, how the literature should be used during this initial stage of a study. In 1967, the originators of grounded theory, Glaser and Strauss, advocated their classic view that the literature review should be delayed until data analysis had been completed. Their reason for recommending this delay was to enable the researcher to avoid importing other writers' ideas and imposing them on the study about to be undertaken. In other words, this was a deliberate attempt to liberate the researcher from previous ideas and to encourage them to articulate their own original thoughts. This view has been robustly maintained by Glaser over the years, who, maintains that delaying the literature review serves to keep the grounded theory researcher as free and open as possible to discovery of theoretical interpretations within the data (Glaser, 1998).

In his later work with Corbin (Strauss and Corbin, 1990), Strauss questioned whether the original grounded theory stance towards the literature review was naïve. Strauss came to believe that it is inevitable that all researchers bring some professional and disciplinary knowledge to the research endeavour. Moreover, it seems likely that at least some of this knowledge will have been gleaned by an acquaintance with the academic literature: it seems reasonable to assume that someone interested in carrying out research will have done some previous reading in their chosen field. Thinkers such as Bulmer, (1979) Dey (1999) and Layder (1998) support this view, having similarly critiqued Glaser and Strauss' original

purist view on the grounds that it is impossible for the researcher to enter the field as a blank slate.

Acknowledging the impossibility of the blank slate researcher, together with the fact that many academic institutions require some sort of literature review within a research proposal, some grounded theorists undertake a limited preliminary literature review. Birks and Mills (2011) see a limited and purposive preliminary review as being advantageous to the researcher in the early stages of their work. In particular, they see this as an effective tool for enhancing early theoretical sensitivity. Strauss and Corbin (1990) define theoretical sensitivity as the researcher possessing the attribute of insight, the ability to give meaning to the data and the capacity to separate the pertinent from that which is not. This comes from experience **and** reading.

Urquhart (2007) argues that a limited preliminary review can serve to orient the grounded theorist to the field of study without necessarily prejudicing them towards existing theoretical ways of understanding their topic. Dunne (2011) concurs with this view, seeing the initial review as a means of achieving the contextualisation of the study whilst simultaneously enabling the researcher to approach the study with an open mind. In a similar way, whilst not discouraging initial reading of the literature, Henwood and Pidgeon (2003) advocate taking a non-committal attitude of theoretical agnosticism towards extant theories as a means of aiding original thinking.

Taking a pragmatic view, Charmaz (2006) considers it acceptable to engage in background reading of significant studies and theories in the field of enquiry, to enable the researcher to outline a general direction of travel and thus satisfy the requirements of research institutions.

However, allowing earlier studies or theories to unduly influence original theory development is to be resisted. She favours letting such material “lie fallow” until after the grounded theory has been substantially developed. It is at this stage that the research is located within the relevant literature. The articulation of the original ideas of the researcher, inducted from the original data, is of paramount importance in a Charmaz approach to grounded theory.

A further and related reason for keeping engagement with the literature limited is that material which is going to be relevant to the particular research study is unknown at the outset of the work. Due to the inductive nature of grounded theory research, literature regarded as relevant at the outset of a study may be deemed irrelevant by the time a substantive theory begins to emerge. Charmaz (2006) envisages a situation whereby the study takes the researcher into new substantive terrain where new literature will become relevant only at this point in time. This is particularly relevant in a study such as this one, which took place over a prolonged period of time, that is, six years, within which timeframe, new literature on the subject became available.

### **2.3 The Use of the Literature within This Study**

This study utilised a Charmaz-influenced constructivist grounded theory approach. Therefore, at the outset of this study, an initial literature review was undertaken with a more substantial literature review being undertaken at the data analysis stage. The initial review served to outline the general path of this enquiry without restricting journeys into original theoretical terrain. In addition, it served to satisfy the requirements of the university research proposal process and helped orientate the study and myself as researcher in terms of enhancing theoretical sensitivity.

Initial engagement with the literature, then, provided a general overview of existing knowledge in this research area. For example, the fact that there is no national template for ascertaining hospice patient and carer views on preferred place of death (PPD) was highlighted. However, possible models of good practice regarding PPD which may be in place in other hospices were not considered in detail before data for this study were gathered.

### **2.3.1 Search Strategy**

Three electronic databases - Web of Science (2004-2008), Department of Health Publications and Statistics (2000-2008) and National Council for Palliative Care (2000-2008) were searched using the search terms palliative care, place of death, patient preferences; ethical issues and quality in palliative care. Studies before 2000 were excluded in order to survey the contemporary context with the exception of one study (Townsend et al., 1990) which was included because of frequency of citation. This yielded a total of 29 papers eligible for review. Each title and abstract was then scrutinised with reference to the subject matter of this study, that is, matters around the PPD of hospice patients. In this way a paper was accepted if it was relevant in some way to the specific subject of the PPD of hospice patients. After this screening process there were 13 papers eligible for review.

Each paper was then full text read and assessed in terms of rigour and relevance to this study remit. An appraisal tool, adapted from the *Critical Skills Appraisal Programme (CASP)*, (Better Value Healthcare, 2013) was devised to aid with this process. The appraisal considered whether the aim of the paper was clear; whether the methodology was appropriate to the study; whether the research design, recruitment and data collection were adequate to address the study aims; whether findings were clear and whether they were

relevant to my study area. Almost all the papers were from the UK as this helped to inform this UK study, with one study from Australia and one from Italy providing a snapshot of issues around PPD outside the UK.

## 2.3.2 Summary of the Initial Literature

**Figure 2.1 Initial Literature Review Table**

Title, Author & Place	Methods	Results	Rigour & Credibility	Relevance
<p>Preference for place of care and place of death in palliative care: are these different questions?</p> <p>Agar, M., Currow, D.C., Shelby-James, T.M., Plummer, J., Sanderson, C. and Abernethy, A.P., 2008. Australia</p>	<p>Longitudinal qualitative observational study of 71 patients and carers</p>	<p>Place of care and place of death are not synonymous</p>	<p>Method appropriate to research and clearly described. Consent described. Secondary analysis of data from larger study – how rich is the data? Excludes patients with no carer. Recruited by nurse – power dynamics?</p>	<p>Issues around use of terms place of care and place of death</p>
<p>Place of death – how much does it matter?</p> <p>Barclay, S. and Arthur, A., 2008. UK</p>	<p>Editorial article arguing for obtaining views of patients experiencing end of life care through survey</p>	<p>Recommends interviews or questionnaires and 6 month post-death survey of next of kin</p>	<p>Good use of current literature to build an argument. Does not address possible difficulties in identifying participants and attrition. Survey will only obtain retrospective data</p>	<p>Hi-lights we know little about current end of life care experiences</p>
<p>Eliciting individual preferences about death: development of the end-of-life preferences interview.</p> <p>Boreani, C., Brunelli, C., Miccinesi, G., Morino, P., Piazza, M., Piva, L. and Tamburini, M., 2008. Italy</p>	<p>Testing end of life preferences interview with 3 palliative care doctors and 49 patients. Semi-structured qualitative interviews with doctors discussing reasons for proposing or not proposing interview with patients.</p>	<p>Out of 49 eligible patients, doctors offered interview to only 12 patients and asked 4 patients about death.</p>	<p>Relevant method clearly described in 3 phases. Interview designed by “experts” – all professionals, patients and carers excluded. Issues around power conferred on doctors</p>	<p>Doctor-patient dynamics in end of life care. Doctors views on end of life care and perceptions of patients.</p>
<p>Place of death. It is time for a change of gear?</p> <p>Constantini, M., 2008. Italy and UK</p>	<p>Journal editorial arguing for finding out ground level view of end of life care.</p>	<p>Argues for various end of life care initiatives to be evaluated</p>	<p>Good use of current literature to build argument. No concrete suggestions offered – just “further research”</p>	<p>Articulates the need to research lived experience of people at end of life</p>

Title, Author & Place	Methods	Results	Rigour & Credibility	Relevance
Factors influencing death at home in terminally ill patients with cancer: a systematic review. Gomes, B. and Higginson, I.J., 2006. UK	Systematic review of 224 articles & 45 papers on factors affecting home deaths of cancer patients	Identified 17 factors influencing home death	Method appropriate and clearly described. Rigorous review, but the reported quality of papers reviewed was highly varied making comparison of data not obvious at first glance.	Baseline data for home deaths. Expressed preferences positively influenced achieving home death.
Choice and place of death: individual preferences, uncertainty and the availability of care.  Munday, D., Dale, J., and Murray, S., 2007 UK	Paper discussing professional issues on delivering preferred place of death	Identifies need for provision of different settings for death and need for good communication skills	Good use of current literature to build argument. Presents professional viewpoint only - does not take user views into account	Raises issue of service provision. Begs questions around patient-clinician relationship & empowerment of patients
Preferred Priorities for Care.  The Department of Health, 2007. UK	Tool for ascertaining patient priorities for care at end of life	A useable tool to encourage patients to write down preferences and priorities & to share this with others	Clearly explains its general purpose. Headings for recording information rather broad e.g. "future care" Does not use word "death"	Includes medico-legal matters which focus on refusal of treatments, but PPD may not be about medical matters. Incentive to engage with this? Use of euphemisms. Take-up rate in palliative care?
Advanced Care Planning: A Guide for Health and Social Care Staff  DH, 2008. UK	Paper highlighting key issues for healthcare professionals of incorporating advanced care planning into practice	Broad statement of wishes, preferences Mental capacity & lasting power of attorney (Mental Capacity Act 2005).	Explains terms and issues clearly. Guidance is clear with case studies; Issues are raised very briefly but clearly with examples of current practice. Recommends further research.  Mentions end of life care but not "death"	Broader focus than PPD including medico-legal matters which may not be relevant in hospice setting. . Incentive for staff & patients to engage? Take-up rate in palliative care?

Title, Author & Place	Methods	Results	Rigour & Credibility	Relevance
End of Life Care Strategy  DH, 2008 UK	Government report advocating discussion around end of life wishes as death approaches	Recommendation of 6 step pathway towards good end of life care	Clear pathway identified Expectation of compliance but no clear template offered	Issues around identification, documentation and review of end of life wishes.
Place of death: preferences among cancer patients and their carers.  Thomas, C., Morris, S.M., and Clark, D., 2004. UK	Longitudinal qualitative observational study of 41 terminal cancer patients and 18 informal carers Series of in-depth qualitative interviews with patients and carers.	Identifies 13 factors shaping preferred place of death in 4 thematic domain. Decisions are contingent	Method appropriate and clearly described. High sample attrition rate. Recruitment reliant on palliative nurse.	Portrays some reasons underpinning people's preferences. Highlights participants' choice of place and tentatively suggests a new trend. Interviews when death very close.
The place of death of cancer patients: can qualitative data add to known factors  Thomas, C., 2005. UK	Summary of epidemiology literature on location of death and semi-structured qualitative interviews with 15 palliative care service providers on place of death factors	Identifies new factors of service infrastructure, patient & carer attitudes, awareness of dying & cultures of practice	Method appropriate and well described. Perspectives from hospice & community only as no hospital palliative care beds.	Provides information for palliative care policy makers and Service providers. This is not lived experience of users but suggests areas to explore with users in further research.
Terminal cancer care and patients' preference for place of death: a prospective study.  Townsend, J., Frank, A.O., Fermont, D., Dyers, S, Karran, O., Walgrove, A. and Piper, M., 1990. UK	Series of structured questionnaires with 84 terminal cancer patients to ascertain preferred place of death. 30 carers interviewed post-death for their assessment of patient's care.	84% of patients stated their preferred place of final care. 70% of carers satisfied patient's wishes met. 28% of carers of hospital deaths wished could have cared for them at home.	Clearly described method relevant to research question. Structured questionnaire left little space for patient-led dialogue. Only unambiguous responses included in data. High rate of attrition due to death or being too ill. Not clear that word "death" was used.	Interviews when death very close. High proportion willing to state preference for final place of care. Method does not allow for in-depth patient voice. Issues of euphemisms. Information on carer's perspectives, but post-death only.



Title, Author and Place	Methods	Results	Rigour and Credibility	Relevance
<p>Preferred Priorities for Care. Your Advanced Wishes.</p> <p>Weston Hospicecare, 2008. UK</p>	<p>Adaptation of PPC - Preferred Priorities for Care Your Advanced Wishes leaflet.</p>	<p>Encourages patients to write down their wishes &amp; to share with others Addresses possible refusal of treatments</p>	<p>Uses the words "death" and "dying" Non-medical prompts &amp; medico-legal content</p>	<p>User-friendly. What do patients and carers think about such a document? When might they want to access it?</p>

## **2.4 Discussion of the Initial Literature**

Considering that the UK government's current health agenda includes the desire to meet patient choice in preferred place for death, it was interesting that this initial literature review showed that there was little research on patient and carer voices on this matter. Of the 13 articles read, only three addressed patient and carer views directly (Townsend et al., 1990; Thomas and Clark, 2004; Agar et al., 2008). Of these three, one used secondary analysis from a larger study (Agar et al., 2008), thus restricting the richness of the data gathered. Another used a highly structured questionnaire with no provision for a patient-led dialogue to emerge (Townsend et al., 1990). The third study started with the a priori premise that home was the best place to die (Thomas and Clark, 2004), with patient and carer views being measured against this standard rather than facilitating a more open-ended dialogue.

Two editorial articles argued the case for obtaining views of patients who are actually experiencing end of life care (Barclay and Arthur, 2008 and Constantini, 2008), noting the dearth of research in this area.

Reasons for the dearth of research from the patient perspective may include difficulties in recruitment and attrition due to the fragile health of such patients and problems associated with researching such a sensitive topic. Nevertheless, the lack of patient voices in this area is notable.

The literature showed that some attention had been given to service providers' views of end of life care. Factors influencing place of death from a service provider's viewpoint such as service infrastructures, cultures of practice (Thomas, 2005) and availability of different

settings for death (Munday, Dale and Murray, 2007) were seen as having a bearing on patients' preferred place of death.

It was perhaps predictable that service providers should establish a research base to aid in the apportioning of resources. However, the fact that this research base did not ascertain the views of service users meant that that services provided on the basis of this research would only address provider concerns whilst service user concerns, that is patient concerns would remain unknown. Therefore, such research would be limited in its usefulness as an aid to planning future services.

Two articles highlighted the relationship between physicians and patients as being significant in the delivery of good end of life care (Munday, Dale and Murray, 2007 and Boreani et al., 2008), with the presence or absence of good communication skills, doctor-patient dynamics, empowerment or disempowerment of patients and the positive or negative attitudes of physicians towards conducting end of life care discussions playing key roles in whether such discussions actually took place. Whilst it was not surprising that the literature noted the importance of effective communication in end of life care planning, the significance of the doctor-patient relationship raised questions around the power dynamics at play.

In recent years there has been a series of government initiatives and tools which could theoretically support end of life care discussions. Four of these initiatives and tools were included in this review: *Preferred Priorities for Care* (NHS, 2007); *Advanced Care Planning* (National Council for Palliative Care, 2008) *Preferred Priorities for Care, Your Advanced Wishes* (Weston Hospice Care, 2009) and *End of Life Care Strategy* (DH, 2008). It is noteworthy that none of these tools or initiatives provides a clear template for facilitating

such discussions. For example, the End of Life Care Strategy (DH, 2008) identifies a clear six step pathway which could enable the identification and documentation of patients' preferences but does not provide a format in which to record such information. In addition, both the Preferred Priorities for Care (2007) and the Advanced Care Planning (2008) documents encourage patients to write down their preferences and priorities but they do not provide pro formas for this. Without some form of concrete documentation, recommending who should take responsibility for end of life care discussions remains unclear.

Furthermore, due to the extremely sensitive nature of this work, tangible prompts and support in the form of documentation may help staff to operationalise such delicate discussions. At the time of this initial literature review, the Liverpool Care Pathway (NHS, 2009) fulfilled this function. The Liverpool Care Pathway was a clinical care document providing staff with prompts and guidelines for best practice in caring for people at the end of life. The perceived usefulness of such an approach can be measured by the high take-up rate by service providers: by 2009, 22 out of 34 cancer networks in England were using the Liverpool Care Pathway, (NHS, 2009).

There was, however, controversy reported in the broadcast media around some misuse of the Liverpool Care Pathway by some clinicians within the hospital setting. This resulted in a government review of its use, which concluded that such an approach works well with well-trained and sensitive clinical teams (Independent Review of the Liverpool Care Pathway, 2012). Subsequently the name Liverpool Care Pathway was dropped and several recommendations to improve end of life care practice and documentation were made. These included better communication between clinicians and patients and their relatives regarding clinical decision making on end of life care and better training on specific clinical matters

around end of life care, such as oral hydration. The basic approach of using documentation to support end of life care, however, was commended and was developed into an End of Life Care Plan for each patient dying in a clinical setting.

Whilst the literature showed that documentation has clearly become part of the end of life planning debate, particular aspects have not been clearly articulated. For example, a recommended format of such documentation has not been defined, whether or not there is a duty to complete such documentation is unclear and the perceived usefulness of recording end of life plans from the perspectives of users and carers and healthcare professionals has not been fully explored.

Since talking about death is a culturally difficult issue it was not surprising to find some reference to terminology and the use of euphemisms for death in several papers. Three papers substitute the word "care" for death (Townsend et al., 1990; NHS, 2007; National Council for Palliative Care, 2008) whereas Agar et al. (2008) conclude that place of care and place of death are not synonymous from patients' viewpoints. The Weston Hospicecare leaflet (2009) does use the word "death". The literature showed that there are issues around terminology in end of life planning. The use of different words such as "death", "care" "end of life" raises questions around why different terms are deployed and exactly what they connote.

The timing of conversations around preferred place of death may also be a significant factor in end of life preferences. All the studies in the literature which reported conversations with patients on this issue had patient eligibility criteria of a prognosis of between two to six months (Townsend et al., 1990; Thomas, Morris and Clarke, 2004; Agar et al., 2008; Boreani

et al., 2008). It would seem that little is known of the views of patients who are living with a terminal diagnosis but who are not so close to death.

A variety of methodologies was evident in the reviewed literature: five papers used qualitative methodology (Thomas et al., 2004; Thomas, 2005; Munday, Dale and Murray, 2007; Agar et al., 2008; Boreani et al., 2008); two used quantitative methodology (Gomes and Higginson, 2006; Townsend et al., 1990); there were two editorial articles (Barclay and Arthur, 2008; Constanini et al., 2008); three tools for recording patient wishes (NHS, 2007; National Council for Palliative Care, 2008; Weston Hospicecare, 2009) and a government report on end of life care in the UK (DH, 2008). Whilst different methodologies were employed, this review showed that across the methodological spectrum, there is now some research into patient wishes and preferences around end of life care, but this is sparse. The limited amount of research from the patient and carer perspective supports the case for further research with a methodology which can capture the lived experience of people faced with making plans for the end of life.

## **2.5 How the Initial Literature Review Informed This Study**

The initial literature review orientated this study towards some issues in the field of palliative patient preferences around place of death. The issues noted in the initial review functioned in two ways. Firstly the topics raised contributed to thinking which underpinned the formulation of research questions. Secondly the various subjects which emerged in the initial review provided some of the topics offered for discussion in the interviews and focus groups, for example documentation was offered as a topic for discussion in both the interview and focus group schedules (Appendix 7; Appendix 6). It is important to emphasise that the shape of this study was not constrained by the initial review, as this study was exploratory

and inductive in nature, and responded to participant insights as they emerged. The initial review served rather as a starting point and a signpost to the general direction of the study.

In particular the following issues which emerged from the review informed this research study in the following ways. The dearth of research on patient and carer voices confirmed the important role of this research study in gathering user-based data through interviews and focus groups with hospice patients, carers and staff. Difficulties in communication between doctors and patients raised in the literature, pointed towards the potential for this to be explored further in this research from the perspectives of hospice staff, patients and their carers. The recent emergence of various end of life discussion tools highlighted documentation as a potential area for exploration with participants, should this emerge as important to them. Similarly issues around terminology used in end of life discussions suggested a possible area for discussion with participants. The deficiency of research on the views of patients living with a terminal diagnosis but who are not imminently dying, confirmed the importance of this study which researched the views of day hospice patients who are generally not so far along the illness trajectory.

Thus the initial literature review influenced the direction of this study in terms of sensitising me to current concerns in this field of enquiry, whilst allowing me to remain open to generating new theory based on data which I would gather (Urquhart, 2007).

## **2.6 Summary**

This chapter has described how the initial literature review of this study was approached and has discussed issues arising from the reading.

Chapter three will describe the research questions and aim of the study and will articulate the research questions.



## **Chapter Three      Research Questions and Aims**

### **3.1      Introduction**

This chapter describes the purpose of this study. It explains why it was important to ask the research participants, that is hospice patients, carers and staff, for their particular views on discussing PPD. The aims of the study and the research questions are then described.

### **3.2      Study Rationale**

The UK Government's End of Life Care (EOLC) Strategy (DH, 2008) states that patients' PPD should be identified, documented and reviewed. The purpose of this research study was to explore the views of a group of hospice patients, carers and staff around PPD. It was important to ask questions about this since the whole area of patient, carer and staff views on this had not yet been explored.

This research could provide an opportunity to explore whether there was a sense of congruence or disconnect between governmental policy on PPD and the grass roots experience of those dealing with terminal illness. For example, this research set out to explore whether or not documenting end of life care preferences was a priority for users and carers; whether or not patients and carers had preferences about place of death; whether they wished to discuss such matters with healthcare professionals and if so at what stage in their illness would they want to have such a discussion. It set out to probe issues around end of life planning conversations for patients, carers and healthcare professionals; knowledge about realistic options for end of life care within current local service provision and any other issues around PPD which arose as important to the patients, carers and staff

of the hospice. This research then, set out to open a forum for discussion of issues around PPD by hospice patients, carers and staff.

The notion of patient choice was highly relevant to this research. Whilst there are many government and health guidelines highlighting the importance of meeting patient choice in PPD (e.g. NHS Act (DH,2006); Health and Social Care Act (DH,2001); NICE Guidance on Palliative Care (NICE, 2004); End of Life Care Strategy, (DH,2008), it was unknown to what extent this is carried out in reality in North Staffordshire or indeed elsewhere. In 2007, government figures suggested that over 80% of Primary Care Trusts were aiming to achieve PPD, by embracing the Gold Standards Framework – an initiative which began in 2001 to enable patients to live and die where they choose. However, in the same year only one third of GPs had in fact put the Gold Standards Framework into practice (NHS, 2001). One study suggested that for many patients, the place of death is by default rather than choice due to lack of planning or service provision or problems with symptom control or carer support (Thomas, Morris and Clark, 2004).

The hospice in this study was philosophically committed to supporting patient and carer choice. Its mission statement says that the hospice aims to ensure that the last stage of an incurable illness becomes a shared journey, helping the patient to die peacefully with dignity and without anguish by relieving pain and other distressing symptoms. However, it did not express a view regarding place of death including issues around choosing a place for death. Indeed the hospice did not systematically record PPD and furthermore there is no national template for recording such information. Current statistics revealed where patients of this hospice died but it was unknown if this was their place of choice. So, despite government initiatives such as the Gold Standards Framework (2001) and the End of Life Care Strategy

(2008), this hospice did not yet directly address the question of patient choice with regard to PPD. This research set out to explore patient and carer views about choice in depth.

In gathering knowledge about choice in end of life care in North Staffordshire, in particular from a user/carer perspective, this research study set out to provide data for analysis which could be useful in a number of ways. This research could enable service providers to better understand patients' wishes which could then inform strategy and planning so that resources could be put to best use. For example, if this research showed that the overwhelming majority of patients wanted to die at home, but resources were currently being put into hospital or hospice beds than an adjustment could be made accordingly when planning future patient services.

In addition, this research could provide an opportunity to consider whether patient choice about place of death really existed and if so to what extent. Issues around how patients accessed choice could be identified and it could raise questions around the education and support of patients on this issue. At a philosophical level, this research had the potential to open the debate on how patients are viewed by those who have a duty of care towards them and indeed how they perceive themselves, whether as passive recipients of care or as partners.

In seeking the views of hospice patients, carers and staff this research afforded the opportunity to discover detailed issues around conducting end of life conversations. For example, from the point of view of the patient, the particular facets which make this an easy or difficult task and whether these views coincide with those of hospice staff who may find such conversations difficult (Barclay and Maher, 2010). Such knowledge could influence how

doctors and nurses discuss this sensitive issue with patients in the future and could inform thinking about the timings of such discussions and whether there might be a need for a series of discussions as the patient's journey along the illness trajectory continues. Thus, this research had the potential to impact on medical and nursing training on PPD matters.

This research afforded the opportunity for the exploration of nuances and issues around terminology used in end of life care planning. Medical terminology in general is often poorly understood by patients (Lerner et al., 2000) and it is unknown whether palliative care terminology in particular is better understood. For example, the terms preferred place of *death* (PPD) and preferred place of *care* (PPC), are both seen in the end of life care literature and the understanding of their usage is debated. In this study, patient, carer and staff perspectives on such terminology and their deployment of these and other terms in end of life planning were examined and considered in order to gain a better appreciation of user and carer comprehension of language in which to discuss PPD. Such knowledge could have implications for both service providers and users and carers. For example the existence or otherwise of a common end of life planning lexicon could provide important insights into the extent of mutual understanding and ultimately the extent of effective communication between service users and providers.

In conclusion, this study set out to investigate this under-researched area of user and carer views on PPD and to explore various issues within this topic area including patient choice; service delivery; the education of patients; the training of doctors and nurses and issues around communication in end of life planning.

### **3.3 Study Aims**

The study sought to address two broad aims:

- To explore PPD from the perspectives of the research participants
- To generate theory about the participants' experience of PPD

#### **3.3.1 To Explore PPD from the Perspectives of the Research Participants**

The study aimed to discover the views of hospice patients, carers and staff around PPD by exploring the experiences and perceptions of these participants. As an exploratory study, this research started from the premise that patient, carer and staff views can only be understood from the patient, carer and staff perspectives, in their own words and from inside their own particular context. Hence, this research took an emic perspective, accessing or 'tapping into' the world of the participants by asking them to describe their experiences on their own terms without recourse to an external frame of reference (Priest and Roberts, 2010). This kind of understanding cannot be known beforehand as it is likened to a voyage of an explorer, seeking out strange new worlds in, as yet, uncharted territory, (Parahoo, 2006).

#### **3.3.2 To Generate Theory about the Participants' Experience of PPD**

This study aimed to generate a substantive theory about the lived experience of PPD.

Substantive theories are generated for the purpose of understanding a specific phenomenon in a clearly defined context (Glaser and Strauss, 1967). The methodology of this research study, that is constructivist grounded theory, was chosen because it afforded the opportunity to offer an interpretative explanation of the participants' concerns regarding PPD within their social context. Theory generating methodology focuses on conceptual abstraction, rather than description, for the purpose of uncovering the social processes at work within the

context. Hence, the decision to adopt this strategy was driven by the desire to offer a theoretical interpretation of what this experience of PPD meant for these participants in this context.

Such a theoretical explanation could serve as a starting point for reactions from practitioners and researchers. In response to this theory, providers of end of life care could take action to develop new models of service delivery and researchers could develop further theory as new knowledge is acquired. Glaser, one of the originators of grounded theory, said of this methodology that it is able to get through and beyond preconceptions about phenomena to the underlying processes of what is going on, so that professionals can intervene with confidence to help resolve the participants' concerns (Glaser 1978). Hence this research set out to generate theory about PPD which could then be used by service providers and researchers in making a response to such theoretical insights.

### **3.4 Research Questions**

The aim of the study was to explore key considerations for hospice patients, carers and staff when thinking about PPD and to generate theory about these experiences. Specific research questions were:

1. Do patients, carers and staff welcome discussions on PPD: why or why not?
2. Is talking about PPD easy or difficult for patients, carers and staff and why is this so?
3. With whom is PPD discussed and what are the issues around this for patients and carers and staff?
4. What issues arise for patients, carers and staff around the timing of

discussions on PPD?

5. How is information about PPD recorded and disseminated across the care team and what are the issues arising from this?
6. What questions do patients, carers and staff wish to explore about PPD?

### **3.5 Summary**

This chapter has stated the rationale for the research and the aims and questions have been presented. Chapter Four will discuss the methodology.

## **Chapter Four      Methodology**

### **4.1      Introduction**

This chapter presents the philosophical underpinnings of this research. My ontological perspective, that is how I view social reality, is articulated. Following on from this, my epistemology, that is my view of how knowledge about the social world can be gained, is outlined. Building on this framework, the reasons for choosing grounded theory methodology are presented.

### **4.2      Ontology**

Ontology concerns how the nature of being is understood. Ontologically I take an interpretivist-constructivist stance, rejecting the positivist perspective which espouses that the world may be understood objectively.

Positivism, emerged towards the end of the nineteenth century, in the thinking of philosophers such as Comte, Saint-Simon and La Place and was, for a long time, the dominant approach to science, including social science. Positivism holds that empirical data are impartial facts which are testable and verifiable and therefore unassailably true. Empirical knowledge, then, is seen as the basis of irrefutable cause-and-effect laws which act as predictors of behaviour. Positivism employs deductive hypothesis-testing methodology, epitomized by controlled laboratory experimentation, with the quantification of data and the maintenance of distance between the researcher and the researched in order to avoid bias.

Whilst the positivist tradition continues to influence research today, especially in the natural sciences, its original uncritical belief in objectivity and the power of controlled experiments to prove scientific knowledge has been modified over time. Polanyi, (1967), pointed out that



even scientists are personally engaged in the world and influenced by it and therefore truly objective knowledge is impossible. Moreover, scientific knowledge is always contingent because old methods are critiqued, new ways are adopted, new data are accrued and eventually one so-called fixed view of the world is replaced by another (Popper, 1959, Lather, 2004). However, a largely empirical, objectivist orientation to research remains dominant in the thinking of some researchers.

In contrast to such a worldview, I take an interpretivist-constructivist approach which does not believe that 'the truth is out there' and the job of research is to find it and report about it. My ontological position is that human beings are not subject to universal laws; on the contrary they construct meaning as they act within their particular social setting.

Furthermore, since humans are unique individuals they each have a unique perspective which they bring to bear on their meaning-making. This allows for different perspectives on phenomena. For example, **my** apprehension of motherhood may be quite different from the meaning given to this experience by my own mother. Both understandings are equally valid, though influenced by different socio-economic and political contexts and different personal responses to the experience of being a mother. Such different interpretations of the same phenomenon are regarded as equally true representations because, within this ontological position, context is important and subjective experiences such as thoughts, feelings and emotions are not outside the realm of scientific enquiry (Brustard, 2008). I stand, therefore, with social scientists who believe that understanding human experiences from the context of their own lifeworld is as important as focussing on explanation, prediction and control (Holloway and Wheeler, 2010).

The interpretivist-constructivist view can trace its roots to nineteenth century developments in philosophy and history which postulated that although the role of natural science is explanation, the role of social science is understanding or in German, *verstehen*. The German philosopher Dilthey (1833-1911) championed the first-person perspective of actors in the field, which gave them their unique understanding. The concept of *verstehen* was taken up by the sociologist Max Weber who argued for social science to relate to research participants on their own terms and from their own point of view, rather than interpreting them in terms of their culture (Macionis and Gerber, 2011). Through reflective reconstruction and interpretation of the action of others, Weber believed it was possible to accomplish something different from natural science, namely the subjective understanding of individuals' actions within their context (Gingrich, 2012).

More recent influences on the interpretivist-constructivist view include postmodernism and social constructionism. Postmodernist thinkers of the 20<sup>th</sup> century such as Lyotard and Derrida stressed the multiplicity of perspectives and rejected the notion of absolute truth, regarding all knowledge as culture-bound and relativistic (Slevin, 2010). Because there are often a variety of alternative explanations for a phenomenon, knowledge was seen as provisional and uncertain (Willis, 2007).

Social constructionism argues that reality is constructed through human activity: it is built by the participants engaged in the process and therefore cannot be sought out and discovered because it does not exist prior to social interaction (Kim, 2006). Additionally, because meaning is constructed within a social context, it is tied and relative to context, time and culture, as opposed to being generalisable (Holstein and Gubrium, 2008). Crotty emphasised the unique experience of every person, regarding each one's way of making sense of the

world as equally valid (Crotty, 1998). In agreement with such thinking, my view, then, is that social reality is not a rational fixed entity, but that people make meaning out of their world in an active way.

### **4.3 Epistemology**

My ontological belief that people construct meaning within their social setting impacted my view of what kind of knowledge should be sought to better understand my research topic (David and Sutton, 2004). Hence my ontological view shaped my epistemology.

My quest in this study was a search for meaning as opposed to facts. Rather than gaining knowledge about what was known about the research participants in a cognitive, factual sense, I sought an understanding of how they interpreted their lives. I looked to the first-hand experiences of the stakeholders themselves, that is the research participants, to provide meaningful data (Laws and McLeod, 2004), believing that through rigorous interpretation I could learn something of the truth of their lives (Byrne-Armstrong et al., 2001).

This quest for interpretive meaning led to the decision to use qualitative methodology. Qualitative research methodology has been described as being a form of enquiry which focuses on the way people make sense of the world in which they live (Holloway and Wheeler, 2010). Therefore, rather than concentrating on ascertaining the facts of the matter, qualitative research plumbs the depths of the facts to search for the meaning of the lived experience. The research topic is explored in order to learn how the particular facet of life is apprehended and understood by those who are experiencing it.

Because the overall aim of the study was to explore the research topic from the perspectives of hospice users and carers, this study required allegiance to the qualitative research paradigm. Such an approach is concerned with developing an holistic understanding of human experience, which many would argue is coterminous with the enterprise of healthcare itself, which aims to be holistic and personal (Priest and Roberts, 2010). Sandelowski (2004) has argued that qualitative research can be particularly appropriate for healthcare research which explores the social construction of illness, the experience and effects of disease, decision making around birth and death, and factors which affect the quality of care.

Qualitative methodology has a particular understanding of the role of the researcher. It is widely acknowledged that researchers are not objective observers of social phenomena because of their social, political and cultural positioning in the worlds they study (Colaizzi, 1978; Burkitt, 1977; Frank, 1977; Walker, Read and Priest, 2013a). Accepting this, I rejected the notion of the researcher as an objective observer and embraced a view of myself as a co-creator of the research, acting in relationship with the participants. Features of such a relationship include continuous negotiation, the sharing of ideas, a non-judgemental attitude on the part of the researcher and a commitment to allowing participants to guide researchers to issues that are of concern for them (Miller and Boulton, 2007). I adopted such a position of acknowledged inclusion in the research in order to gain access to the true thoughts and feelings of the participants.

#### **4.4 Methodological Choice: Constructivist Grounded Theory**

The particular approach to qualitative methodology which I adopted in this study was Grounded Theory (GT). Grounded Theory is a systematic, inductive, iterative and interactive

method of collecting and analysing data to generate substantive theories. These theories offer answers to 'Why Questions' from an interpretive stance (Charmaz, 2012).

This methodology does not start with a theory which it then attempts to verify, but starts with an area of study and then allows theoretical constructs to emerge from the process of data collection and analysis. Thus, the eventual theory is grounded in the data and therefore relevant to the area under study. Analysis proceeds by constant comparison: by continually comparing data, constructs or categories are identified and the relationships between them are specified in terms of the social processes at work within the particular context (Morse and Richards, 2002). Thus the theory is inductively derived from the researcher's observations and thinking around the phenomenon studied.

The inductive nature of grounded theory accorded well with my ontological and epistemological stance as it enabled the exploration of the lived experiences of research participants, focusing on uncovering the meanings that people attached to their experiences (Wilson, 2012).

The uncovering of meanings by the gathering of data for this study constituted new knowledge. GT has long been judged to be a good method for gathering new information about a topic where not much knowledge existed (Holloway & Wheeler, 2010). Very little was known about the subject matter of this research, PPD, from the participants' perspectives: death preferences were not routinely discussed and recorded at the hospice in the study and there was a lack of knowledge about whether patients wished to have such discussions, and if so with whom and at what stage. Knowledge about how patients think healthcare professionals should broach this subject with them and about what issues this

may or may not raise for hospice staff was also lacking. Therefore, Grounded Theory was a most appropriate means of finding, as yet undiscovered, information about hospice patients' views on preferred place of death (Walker, Read and Priest, 2013b).

GT's primary focus on theory development, rather than rich description, was important because this research aimed to present an interpretive account of one UK hospice's engagement with the topic of preferred place of death (PPD) in terms of illuminating the meanings that participants attached to their experiences and the underlying reasons shaping their meaning-making. The study aimed to produce a substantive theory about the experience of PPD by identifying the basic social process occurring in this context (Alston and Bowles, 2003).

This concurs with GT's aim of discovering the underlying social forces shaping human behaviour (Roberts and Priest, 2010). This aim owes much to its roots in symbolic interactionism, a sociological perspective which holds that people construct selves, society and reality through interaction (Blumer, 1971).

Adopting a sociological approach was in keeping with the research's remit. This was to investigate the topic of preferred place of death from the perspectives of hospice staff, patients and carers as they interacted with the context of wider society, that of an NHS policy stating that hospice patients' preferred place of death should be ascertained, documented and reviewed (DH, 2008). Embracing this basic sociological standpoint gave a sense of theoretical underpinning to the choice of this methodology: the eventual grounded theory would present an authentic interpretive portrayal of the lived experience (Guba and Lincoln, 1994).

Since its beginnings in the 1960s, a number of alternative versions of grounded theory have been developed. Glaser and Strauss's original version articulated systematic methodological strategies for working with qualitative data in *The Discovery of Grounded Theory* (Glaser and Strauss, 1967). Strauss and Corbin (1990) later modified these original ideas, describing step by step procedures of grounded theory. This was subsequently challenged by Glaser (1992), who did not consider their approach to be true grounded theory but conceptual description. Charmaz (2011), has since developed a constructivist version of grounded theory arising from an ontological and epistemological position which sees reality itself as a construction and research activity as active meaning making. Charmaz rejects the idea that theory is something which exists in the data and is discovered by the researcher in favour of the view that theory is constructed by the researcher's interactions with participants, perspectives and research practices. Hence, for Charmaz, any grounded theory is one of many possible constructions of reality.

Standing free from a view which says reality is a fixed phenomenon, it is perhaps not surprising that Charmaz also stands free of any version of grounded theory which prescribes any pre-set scheme or recipe for achieving its aims. Rather, Charmaz espouses a set of systematic yet flexible guidelines for collecting and analysing qualitative data to construct theories grounded in the data themselves. Such guidelines can be adjusted by each researcher in line with their particular context and set of circumstances.

This research adopted a Charmaz-influenced version of constructivist GT for a number of reasons. Charmaz's notion that research activity is concerned with meaning-making accorded with my ontological belief that people actively construct meaning within their social world. Similarly, my epistemological search to generate theory around an understanding of

how the research participants interpreted their lives, fitted well with Charmaz's explicit standpoint that any theoretical rendering offers an interpretive portrayal of the world which is being studied rather than an exact picture of it (Charmaz, 2000). Charmaz's focus on the place of the researcher in the eventual theory and their relationship with the participants (Charmaz, 2006), matched my acknowledged stance as a co-creator of this research, acting in partnership with the participants. Furthermore, the flexible approach to theory generation offered by Charmaz with the injunction that each researcher should concentrate on their own analysis and to construct an original theory that interprets their specific data (Charmaz, 2000), appealed to my desire to generate a creative and unique constructivist grounded theory.

#### **4.5 Summary**

If all research is interpretive because it is guided by the researcher's set of beliefs and feelings about the world and how it should be understood and studied (Denzin and Lincoln, 2005), then it is important to be explicit about my own beliefs and feelings about such matters. Therefore in this chapter I have set out my ontological and epistemological perspectives and given reasons for my methodological choice.

Chapter five will describe the methods and procedures of the study.



## **Chapter Five            Methods and Procedures**

### **5.1     Introduction**

This chapter describes the methods and procedures of this study. The justification for the selection of the research site and sample sought is presented and the ethical approval process is described. The methods of data collection employed in the study, that is, focus groups with hospice staff and semi-structured interviews with patient and carers, are described and matters pertaining to theoretical sampling are presented.

### **5.2     Selection of the Research Site**

This study was situated in a hospice located on the edge of a substantial conurbation in the Midlands in the UK. I decided to undertake this research project at this specific site because my original idea concerned writing a paper on the death location of **this** hospice's patients with regard to PPD and not the death location of hospice patients in general. So the original idea was site-specific. There were a number of advantages to this.

Firstly, I already knew the baseline data from which my particular research questions sprang, that is, I already knew the death location of this particular hospice's patients. The situation at an alternative research site could have been quite different.

Secondly, my chosen research methodology of constructivist grounded theory places considerable value on knowledge of the contextual setting of a study (Laws and McLeod, 2006) and the grounded theorist's possession of skills associated with theoretical sensitivity (Glaser, 1978). Strauss and Corbin (1990) define theoretical sensitivity as the researcher possessing the attribute of insight, the ability to give meaning to the data and the capacity to separate the pertinent from that which is not. For Charmaz, taking a constructivist approach

means learning how, when and to what extent the studied experience is embedded in larger and often hidden positions, networks, situations and relationships within the context of the study (Charmaz,2006). This comes partly from experience: hence Charmaz advocates getting as close to the inside of the experience as we can get (Charmaz, 2006). My years as a chaplain in the hospice meant I was very familiar with the day to day events in the life of this institution: I was sensitised to this specific context, its cultures of practice and the subject matter of the research (Bonner and Tolhurst, 2002; Smyth and Holian, 2008).

Thirdly, as a recent employee in good standing with the hospice, there was a realistic possibility of gaining access to this research site and its potential participants (Slevin, 2010). Gaining access to research sites and participants by establishing trust that comes from on-going relationships and reciprocities with the institution in which the research is situated, is promoted by Charmaz as an effective means of maximising the chances of obtaining telling data (Charmaz, 2014).

As research of any kind had never been carried out at this hospice before, the openness to my 'getting in and staying in' (Adler and Adler, 1987), was advantageous. This was particularly important as the research topic of talking about choosing a place for death was sensitive and potentially distressing and this research population was considered vulnerable. According to the Department of Health (DH), a vulnerable adult is defined as someone:

"who is or may be in need of community care services by reason of mental or other disability, age or illness; and who is or may be unable to take care of him or herself, or unable to protect him or herself against significant harm or exploitation"" (DH, 2000.p.8).

Hospice patients, living with a terminal diagnosis and who are in the latter stages of life clearly fall into this category. Similarly, the informal carer participants of a hospice patient whose illness was deteriorating, could also be regarded as vulnerable. Although professionals in the field of palliative care, hospice staff participants could also become vulnerable due to the potential impact of taking part in intensive discussions on end of life care. For example, reflecting in this way on what have been called the complexities and compromises of real life professional practice (Edgar and Pattinson, 2011) might expose deep emotions in some staff members, particularly, if the discussion revealed less than perfect practices at the hospice.

Therefore as the research population was a vulnerable one, and the topic was sensitive, I expected to encounter a certain amount of gatekeeping with regard to gaining access to them (Walker and Read, 2011). Gatekeepers in this context are parties with an interest in ensuring that ethical standards are upheld and with some degree of influence over the granting of access to the potential study population.

It can be argued that robust monitoring of research is necessary in order for the public to have confidence that no research that might be harmful to participants is undertaken (Cowan, 2009). Building on this, it can be further be argued that accessing the vulnerable populations that are the subjects of such research *should* be difficult, because such participants must be sheltered from research that might be insensitive, intrusive, or potentially distressing (Walker and Read, 2011).

On the other hand, it can also be argued that there is a moral imperative to conduct research of this nature, and that being prohibited from doing so (by gatekeepers) may itself be

unethical in that it would deny patients the possibility of obtaining the best care in the place of their choosing (Parahoo, 2006). Correspondingly, unless vulnerable populations participate in health and social-care research, their requirements and opinions may not be heard (Walker and Read, 2011).

The desire for user and carer voices to be heard on the sensitive issue of preferred place of death was the motivation for negotiating the gatekeepers in this setting who had the power to both facilitate access to participants and bar the way (Emmel, 2007). In this setting in addition to the university peer-review committee and the NHS Local Research Ethics Committee (LREC), the gatekeepers were the hospice Chief Executive Officer and Medical Director, a hospice user group (The Patients' Forum) and the hospice Clinical Governance Operations Group. These individuals and groups combined to provide objective scrutiny of my research proposal in order to protect the vulnerable from abuse or harm and to ensure that the research was conducted to a high standard.

Part of my strategy for negotiating this nexus of gatekeepers was to ensure that the research would be carefully planned in order to minimise distress to participants. The research proposal clearly demonstrated that the risks of causing distress to participants could be managed through careful study design, e.g. by putting in place measures such as stopping an interview if the participant became distressed, debriefing the participant after the interview, and facilitating access to support networks at the hospice and elsewhere. In agreement with Crawford et al (2002), who noted a positive effect on the self-esteem of patients involved in the planning and development of health care, I also made the case that there might be benefits to the research participants, including having the opportunity to talk about this sensitive issue, having their views listened to and valued, and having the opportunity to

contribute to research that might improve patient services as well as future medical and nursing training on end-of-life care.

In addition, I committed to seeking the views of potential participants prior to the commencement of this study by having a number of discussions with the hospice patient group, *The Patients Forum*, to ascertain their views on the idea of researching into the topic of PPD. In taking this action, I was mindful that user involvement in the approval and design process must be genuine and must allow for users' views to be expressed (Maslin-Prothero, 2000).

My interactions with the various gatekeepers were largely beneficial and served to positively refine the study design and safely facilitate access to the vulnerable population. It helped in this respect that there was user involvement from the outset. Indeed accessing users and carer views at the very beginning of this approval process was perceived as good practice and applauded by members of the LREC panel.

Therefore my experience with the gatekeepers was positive in that access was successfully granted to the research population with due regard to the safeguarding of those who were vulnerable, with risks and benefits to them being carefully scrutinised and assessed. At the same time, it was noted that the potentially paternalistic nature of gatekeeping, in preventing participants from speaking for themselves or exercising agency in their own right, was successfully avoided (Miller, 2002).

The trust invested in me due to my recent employee status, was helpful in communicating effectively with various gatekeepers at the hospice. The Chief Executive Officer (CEO)

expressed confidence in my professional expertise in dealing with vulnerable hospice patients and sensitive subjects. This confidence in me was reiterated by the hospice Clinical Operations Group. The Medical Director was supportive of the research, despite studies suggesting that physicians are reluctant to discuss end-of-life care issues with patients (Townsend et al., 1990; Borreani et al., 2008). Having worked with me in the clinical setting, the Medical Director echoed the CEO's confidence in my ability to conduct this research in a sensitive manner. She also identified the research as having the potential to assist in developing best clinical practice within the hospice.

On the recommendation of the medical director I sought the views of the patients' user group, The Patients' Forum. As their opinions were taken seriously at the hospice, the Patients' Forum was a kind of *de facto* gatekeeper. Moreover working with them at the outset of the study provided an effective means of including the voices of the vulnerable at the very heart of this research (Combes and Tan, 2010). Some of the members of the Patients' Forum had known me as chaplain and were keen for patients to take part in a study which could contribute to the development of patient services.

However, they raised specific objections regarding the wording of the invitation letter and consent form. Initially they did not want the word 'death' to appear on the consent forms and felt that the invitation letter was too blunt and that prospective participants would need more explanation of why the research was being carried out. This critique was immensely helpful in refining the documents and meant that user involvement in the approval process addressed the issues central to the user's concerns (Maslin-Prothero, 2000) rather than being tokenistic (Read and Maslin-Prothero, 2011). Additionally, the discussion with the

Patients' Forum resulted in the collaborative presentation of a poster at a *Help the Hospices Conference* (Walker and Flanagan, 2009).

In these ways, being a recent employee of the hospice helped successfully steer the research through the network of hospice gatekeepers. It is noteworthy that this cast me in the role of near-insider researcher. An insider researcher has been defined as one who chooses to study a group to which they belong, as opposed to an outsider researcher who does not belong to the group they choose to study (Breen, 2007).

The literature around insider-outsider research recognises that there are advantages and disadvantages to being an insider research, or in my case a near-insider research. Some writers argue that the value of insider research resides in its ability to draw on the experience of the researcher as a member of the researched organisation and that including the researcher's experience means the study can generate a more complete and distinctive knowledge (Coghlan, 2003) which outsiders could never produce. Much is made of capitalising on previously established rapport and the researcher's ability to act naturally with the participants, (Bonner and Tollhurst, 2002), which in turn greatly assists the researcher in inhabiting the role of co-creator of research (Charmaz, 2006).

On the other hand, there can be a danger of loss of objectivity if insider researchers inadvertently make erroneous assumptions based on prior knowledge and expertise (DeLyser, 2001) or if researchers take data at face value and adopt a non-critical stance towards it (Pitmann, 2002). Familiarity can also be a problem if participants assume that the researcher already knows their view. Kanuha (2002), an insider researcher, reported that it was only on reading interview transcripts that it became apparent that some meanings were

communicated via a shared understanding of vague comments, innuendoes and incomplete sentences and descriptions, whereas a stranger may have been more easily able to critically interact with interviewees as they would be unaware of unquestionable “truths” (Breen, 2007).

Whilst, I believe that my near-insider status was of great advantage to this study, the potential disadvantages of such a role which could have adversely affected this study were considered from the outset. Accordingly, the possibility that greater familiarity with the research context and subject under study could potentially lead to a loss of objectivity on my part, was considered. For example it was recognised that due to expectations arising out of previous experience, I may have failed to recognise the significance of certain information gathered in the course of the study. Unluer (2012) refers to this as the danger of not seeing what is truly present in the study and overlooking the importance of certain routine behaviours or information. Similarly the danger that I may have failed to receive pertinent information due to suppositions on the part of hospice staff or patients, for example on what was considered shared, extant knowledge due to my previous chaplaincy role was also recognised and off-set by various measures.

One key measure which enabled a critical and more distanced perspective to be an integral part of this research, was that I worked closely with supervisors who were not insiders at the hospice. Their more distanced perspective was brought to bear in a number of ways. Firstly in actively co-moderating the focus groups, supervisors were able to immediately draw attention to topics which were being raised by participants which could usefully be probed for further information during the course of the focus group.



Additionally, the decision was made to collaboratively review all data analysis with the supervisory team. This meant that all tentative analysis was subject to ideas and observations by supervisors, including suggestions to explore certain topics more deeply in subsequent focus groups or interviews by altering or adding questions to focus group and interview schedules in order to start to test out or fill tentative categories of the emerging theory. Thus at every stage of this study, a range of perspectives, wider than my own were brought to bear on the research.

Furthermore, any potential bias on my part was confronted within the pages of a reflexive research journal in which I critically reflected on my own perceptions of the research process and in which research decisions were noted. Thus in addition to opening a window on my research activities, thoughts and interactions (Walker, Read and Priest, 2013a), the research diary acted as repository for an audit trail.

In the research diary I was also able to record both negative and positive incidents encountered as a near-insider researcher. On the more negative side, although I judged that I had been careful to underline to participants that my role was no longer one of hospice chaplain, but researcher, the diary records a small number of conversations in which members of staff asked for my advice as their chaplain. This did not interfere with the research and I dealt with such requests by respectfully referring the staff members to their current chaplain. These experiences were, however, a little frustrating as I was left wondering how effectively I had communicated my new role as researcher. On the more positive side, the diary bears witness to the ease with which I was able to liaise with hospice staff in terms of administration regarding recruitment of participants and the booking of hospice facilities for focus groups and interviews. Furthermore, I record how I was able to

use my experience as a skilled listener to good advantage in facilitating the interviews and focus group discussions.

Additionally, I committed to reporting the eventual findings at the hospice: this acted as a further stimulus to guard against any misrepresentation of participants' views and to strive for a sufficient level of credibility. This meant I was committed to producing findings within which participants would be able to recognise the meaning that they themselves gave to their experiences (Holloway and Wheeler, 2010). In striving to ensure that the eventual theory would make sense to the participants and would offer them deeper insights about their lives and worlds, I was committed to Charmaz's concept of resonance (Charmaz, 2011).

On balance, the advantages of being a near-insider researcher outweighed any potential disadvantages: it contributed positively to gaining access to the participants and the smooth running of the study; my knowledge of the research area and hospice context enhanced my theoretical sensitivity and my skills as a former chaplain aided in facilitating data gathering. Potential disadvantages were acknowledged and managed.

My commitment to thinking critically with regard to my near-insider status, including the research process, relationship with participants and the institution and the quality and richness of the data acted as a safeguard against privileging or non-privileging my near-insider status (Jacobs-Huey, 2002) and thus enhanced my commitment to producing worthwhile research. Therefore, attention to matters of insider research and credibility meant that quality standards were built into the design of this study and demonstrated this study's successful interface with matters of rigour (Walker, Read and Priest 2013a).

### 5.3 The Sample

The sample for this study was sought in order to provide rich qualitative answers to my research questions which concerned exploring issues around PPD from across the spectrum of hospice experiences. Hence sampling was oriented towards theory construction, rather than towards other considerations such as population representativeness (Charmaz, 2006).

Focus groups served to bring together a cross-section of hospice staff who worked with patients, whilst semi-structured interviews captured the views of day hospice patients and carers of day hospice patients. Every potential participant approached for recruitment was considered capable of providing rich qualitative data around the issue of preferred place of death since each potential participant had some experience of end of life care either by virtue of living with a terminal diagnosis and a time-limited prognosis, or of caring for a terminally ill person in either a professional or informal capacity.

The aim of the focus groups was to explore hospice staff views, experiences and feelings around PPD. Eliciting staff views was seen as a key part of seeking to gain a rich understanding of people's lived experiences and perspectives, of those situated within the context of their particular circumstances and settings (Murphy et al., 1998). Hospice staff were uniquely placed within this research context, as clinicians. Therefore, via staff focus groups it was possible to explore if and how professional factors affected their experiences and views around PPD of hospice patients. The aim of the patient interviews was to explore the views of hospice patients around preferred place for death. This involved exploring whether patients had considered choosing a place for their death and the factors which might influence such decisions. The aim of the carer interviews was to explore the views of primary carers of around PPD for hospice patients. This included exploring whether carers had had

any conversations on this issue with their associated patient and particular factors which might come into play for them in their unique position as carer.

A further incentive for seeking this sample was that the views of this vulnerable research population on this sensitive issue had not been sought before. I believed that assisting such a vulnerable population to participate in health and social care research was important as it was an avenue for learning about their requirements and opinions (Walker and Read, 2011).

#### **5.4 Ethical Approval**

The study was submitted to the university peer review process and the NHS Local Research Ethics Committee (LREC) for approval. The university peer review process proved to be rigorous. In addition to questioning the scientific rationale of the research, the panel also wanted to see much more detail of the specific objectives and mechanics of the study, and these concerns were directly related to the potential vulnerability of the proposed participants. For example, the panel wanted to know exactly why the research population consisted of day hospice patients rather than in-patients. This was because in-patients were considered more vulnerable, as they may be close to death. The panel wanted tighter inclusion/exclusion criteria and they wanted clarity regarding how many times participants would be contacted and why. Approval was granted in July 2009.

Following approval by the university peer review committee, the study was submitted to the LREC. This involved the completion of a rigorous online form, followed by a formal interview. However, many of the LREC's questions covered the same ground as the peer review process, which helped to speed up the form-filling. Indeed, this particular LREC recommended undergoing peer review first, as a guide to the standard of work required. The

outcome of the LREC, although rather daunting, did not require revisions. Clarification was sought, however, on the procedures in place for gaining consent, issues around confidentiality and support for participants should this be required.

With regard to consent, participants were required to give informed written consent in order to take part in the research. They each received a letter of invitation (Appendix 1), an information sheet (Appendix 2) and a consent form (Appendix 3) in their initial mailing. The information provided clearly explained the nature and purpose of the research; it listed potential benefits and risks to participants; made clear that participation was entirely voluntary and that they could withdraw from the research at any time without giving a reason. For patient participants, it was made clear that taking part in the study did not affect any treatment that they may be receiving from the hospice. In addition, those who volunteered to become participants met with the researcher to ask any questions and agree consent. At the beginning of the focus group or interview, all participants were required to give written consent to the proceedings being audio recorded and at the end of the discussion written consent for direct quotations was obtained (Appendix 4). These measures satisfied the LREC's stipulation for a two staged consent process.

Regarding confidentiality, it was clarified that participants' names and identities were anonymised at the transcription stage. The panel was informed of action to be taken should confidentiality be breached.

Concerning participant support, it was clarified that at the start and end of an interview or focus group, I would provide information about how to access helping agencies at the hospice and elsewhere, should any participant find it valuable to talk about this subject

further. Details of these agencies were made available via a Further Support Sheet (Appendix 5). In addition, the LREC panel asked about contingency plans should a participant become distressed during the course of an interview. In order to deal with such a scenario, I would ensure that the participant was aware that the interview could be stopped immediately if they became distressed and wanted to stop. However, drawing on professional experience of several years as a hospice chaplain, I was able to confirm that for some people, a measure of distress during an interview might not necessarily indicate that they wished to terminate the encounter, but merely required a few moments to recover before continuing. The LREC accepted that I was qualified to make such a judgement call should the situation arise.

Approval was granted in March 2010. An interesting and rewarding facet of this interaction with the LREC was that the committee identified as good practice the work with the hospice patients' user group in refining the study design.

## **5.5 Data Collection**

### **5.5.1 Hospice Staff Focus Groups**

Focus groups have been described as a way of collecting qualitative data, which essentially involves engaging a small number of people in an informal group discussion (or discussions), 'focussed' around a particular topic or set of issues (Wilkinson, 2004). This assists researchers in collecting data from multiple individuals simultaneously. Focus groups are less threatening to many research participants than one to one interviews, and this environment is helpful for participants to discuss perceptions, ideas, opinions, and thoughts (Krueger & Casey, 2000).

A particular strength of the focus group method is the exploitation of group dynamics (Freeman, 2006) with interactions between participants being seen as the key to the method (Kitzinger, 1994). The idea is that group processes can help people to explore and clarify their views and attitudes efficiently, and encourages participation from those who may feel that they have little to say (Kitzinger, 1995). The interpersonal communication between participants additionally helps to clarify similarities and differences in expressed opinions and/or values. The focus groups in this study provided data about the interpretive perspectives of a diverse group of hospice staff regarding PPD. This data was integral to the eventual grounded theory which provides interpretive rendering of the experience of hospice staff, patients and carers (Charmaz, 2006).

The fact that each focus group was analysed immediately after it took place in order to assess the meaningfulness of insights gleaned, was part of the constant comparative analysis of this study and adhered to the precepts of theoretical saturation (Onwuegbuzie et al., 2009). Additional sampling was then carried out, if necessary, via further focus groups and interviews in order to refine and fill the tentative categories which emerged from the first focus group, until such a time as theoretical saturation had been reached (Charmaz, 2000).

There is debate about the optimal number of participants for a successful focus group, with many practitioners suggesting between 6 and 12 participants (Baumgartner, Strong, and Hensley, 2002; Johnson and Christensen, 2004; Krueger, 2000). The rationale for this range of focus group size stems from the fact that the aim of a focus group is to include enough participants to yield diversity in information provided, yet they should not include too many participants because large groups can create an environment where participants do not feel

comfortable sharing their thoughts, opinions, beliefs, and experiences (Onwuegbuzie et al., 2009).

Some of the literature argues for numerically small focus groups to prevent disorderly and unfocussed fragmentary data. For example Krueger (1994) perceives a potential danger of large groups fragmenting into smaller parallel discussions. Additionally, in larger groups, some participants may feel excluded or feel that they are a source of unintended or undesirable effects on group dynamics and a large number of participants may be difficult to facilitate (Fern, 2011).

However, smaller groups may detract from the advantages of collectivism (Priest and Roberts, 2010) and thus not contain enough diversity to provide an opportunity for the positive effects the group dynamic to come into play which could yield rich data for the building of theory. In conjunction with supervisors who were experienced practitioners of focus group methods of data collection it was decided to aim to recruit between 8 – 12 participants to each focus group. The predicted sample size of around 10 participants per focus group was considered small enough to facilitate ease of expression of thoughts, feelings and experiences on the research topic, but large enough to represent a range of views.

The inherent challenge in managing larger focus groups, that is, that it can be difficult to facilitate a discussion amongst a large number of people, was taken into consideration in this study design. Sim has noted that the skills and attributes of the moderator has the potential to exert a powerful influence on the quality of the data collected in a focus group (Sim, 1998). My many years' experience of leading multi-professional team discussions including groups



of 10 or more people meant I possessed the transferable skills necessary to moderate a relatively large focus group.

Furthermore, it was decided to have a moderating team consisting of two moderators per focus group: a moderator (myself) and co-moderator (PhD supervisor). My role as moderator included responsibility for facilitating the discussion, prompting members to speak, requesting overly talkative members to let others talk, and encouraging all the members to participate. In contrast, the co-moderator's responsibilities included recording the session via a digital recorder; creating an environment that was conducive for group discussion, for example in dealing with latecomers, being sure everyone had a seat; arranging for refreshments; observing the proceedings, taking notes and suggesting interventions which informed potential emergent questions to ask the group (Krueger & Casey, 2000).

Furthermore, it was felt that any disadvantages of having relatively large focus groups would be offset by the fact that the staff within this hospice were experienced in working together as a multi-disciplinary team, with different professionals' views being taken into account by the whole group. Thus, in this particular research context, it was felt that the larger group dynamic would aid reciprocal sharing and building on each other's responses within the discussion as a means of yielding rich data for analysis (Greenbaum, 1998).

Moreover, the fact that the staff participants already worked together was seen as an advantage. The staff focus group comprised a pre-existing group with a pre-existing common purpose of care of hospice patients and thus the research could gain from the situated nature of the interactions within the group (Kitzinger, 1994).

Possible problems with group dynamics, in particular the potential for existing hospice culture to exert an undue influence and for senior participants to inhibit free discussion, were noted and discussed within the research team prior to the focus groups. The fact that I was alert to such potential problems combined with the strategy of having a co-moderator who was also experienced in managing group discussions meant that this approach to conducting focus groups was robust enough to counteract any negative effects which might emerge during the course of the groups. Therefore the most important factor in determining the number of participants in the focus groups was getting the right balance of participants, in terms of manageability and potential contribution (Priest and Roberts, 2010).

A hospice practice development nursing sister contacted hospice clinical staff with a view to taking part in a focus group on the topic of PPD of hospice patients. An invitation letter (Appendix 1) and an information sheet (Appendix 2) were supplied to potential respondents and a cross-section of hospice staff were recruited to two focus groups (n=10; n=12) .

Twenty two members of hospice staff took part in two one hour focus groups (n=10; n=12). Seeking to find a balance between well-defined inclusion criteria (Morgan, 1998) and the necessity of forming focus groups which would be sufficiently heterogeneous in order to illuminate the research question from all sides (Holloway and Wheeler, 2010), the following inclusion and exclusion criteria were used:

Inclusion criteria:

- hospice staff who work with patients, for example, doctors, nurses, therapists, social workers, chaplains, healthcare support workers.

Exclusion criteria:

- Hospice staff who do not work with patients, for example, fundraisers, finance office workers, secretaries and administrators, catering and cleaning staff.

The professions of the twenty two staff members recruited to the focus groups are shown in Figure 5.1

**Figure 5.1 Professions from Multi-Disciplinary Team Represented in Staff Focus Groups**

<b>Profession</b>	<b>Number of participants</b>
In-patient Unit Healthcare Assistant	2
Social Worker	2
Clinical Psychologist	1
Doctor	2
In-patient Unit Nurse	6
Day Hospice Sister	1
Community Palliative Care Nurse Specialist	3
Hospice at Home Nurse	1
Practice Development Sister	2
Student Nurse	2

I facilitated the focus group discussion, using the *Focus Group Schedule* (Appendix 6) to initiate and guide the discussion, but I remained open to allowing the participants to discuss

any relevant subject areas arising from the group interaction. The co-moderator took notes which were discussed later and they prompted me with procedural assistance as required. Both focus groups were audio recorded and transcribed for analysis at a later date.

The first focus group was conducted on 6<sup>th</sup> June 2011 (n=12). I briefly explained that the purpose of this discussion group was to explore the topic of preferred place of death of hospice patients from a hospice staff perspective. This included exploring professional factors that may support or negate patients' choices about where they are cared for at the end of life. I explained that the focus group would last for no more than one hour.

I opened the discussion with the following question: *Can you describe what kinds of experiences you may have had as a professional in supporting patient choice?* The discussion soon flowed with members responding and reacting to each other's comments and all members contributing something. I generally allowed the conversation to develop without too much direction. However, interventions based on the focus group schedule questions (Appendix 6) were made in order to ensure that key areas of the research topic were opened up for group discussion including staff reactions to the End of Life Care Strategy (DH, 2008) recommendations regarding ascertaining documenting and reviewing PPD; issues around talking to patients and other professionals; issues around patients preferences and the impact of this subject on hospice staff.

The second focus group was conducted on 24<sup>th</sup> June 2011 (n=10). This focus group was conducted in a similar manner to focus group one. However, in addition to the *Focus Group Schedule* questions, certain areas of interest were probed with this group in order to test out early theoretical ideas, which had emerged during the initial coding of focus group one. This

testing out and verifying early theoretical ideas is entirely in keeping with a grounded theory approach in which the constant comparison method is integral. (Glaser and Strauss, 1967, Charmaz, 2006). The constant comparative method generates successively more abstract concepts and theories through the inductive processes of comparing data with data, data with category, category with category and category with concept (Charmaz, 2006).

### **5.5.2 Semi—Structured Interviews with Patients and Carers**

Semi-structured interviews were used to elicit the views of day hospice patient participants and informal carers of hospice participants, that is, the relative or close friend of a hospice patient. Semi-structured interviews are the verbal questioning of study participants, with a combination of pre-set questions and follow-up probes (Sechrist and Pravikoff, 2002).

Charmaz considers interviews an effective constructivist grounded theory method because they are open-ended yet directed, shaped yet emergent and paced yet unrestricted and provide an opportunity to explore an aspect of life about which the interviewee has substantial experience and often considerable insight (Charmaz, 2006).

An interview schedule was used as a guide and prompt to assist the participant to talk about the research topic. The interview schedule provided broad brushstrokes to guide the interaction in order to maintain the purpose of the exercise, but not to place constraints on the conversation. On the contrary, the participants were encouraged to talk about any relevant issues they wished to explore. Therefore the interviews did not follow an identical pattern, but varied according to the interests of the participants.

Such an idiosyncratic approach lent itself very well to the concept of theoretical sampling which was integral to this research (Charmaz, 2006). As with the focus groups, each

interview underwent initial analysis before the next interview took place. This happened to enable the initial analysis to inform the shape of the next interview. For example, if a certain area of potential theoretical interest emerged during initial coding of a certain interview, this was further probed and explored in the next interview, thus fulfilling the Charmaz guideline to try to understand what is happening from the very beginning of the research process (Charmaz, 2006).

Because the interviews were to be analysed according to a constructivist grounded theory approach, a formal sample calculation was not used. The decision about how many interviews to conduct was made in a similar way to the decision about the number of focus groups, that is, in accordance with the principle of theoretical saturation within a constructivist grounded theory approach. The experienced supervisory team suggested a guideline of 8-12 interviews as likely to be sufficient to yield rich data for analysis, but the exact number was not pre-specified beforehand and the final number was judged when there was enough data to build a convincing theory (Morse, 1995). Therefore I hoped to recruit a pool of around 8 – 12 patients, willing to have an interview and a pool of 8-12 carers.

With regard to recruitment of patient participants, 20 patients were selected by the Day Hospice Manager as potential participants out of a total pool of 75. These 20 patients were judged to be most likely to agree to participate in the study on the grounds that they were regular attendees at Day Hospice and their current health status was regarded as reasonable and stable.

The hospice carers proved a hard group to engage as research participants. This problem was not specific to this study: indeed the difficulties of attracting carers of palliative care

patients into research studies is well documented (Steinhauser et al., 2006; Dobratz, 2003; Sherman et al., 2005). Reasons for this include the heavy burden of care duties carried, resulting in a lack of time for research activities and the need for complete time off from all things palliative in any allocated free time.

Additionally, the Day Hospice staff felt they had limited contact with carers as most patients attended the Day Hospice independently of their carer. Six carers, however, had joined the recently formed Carers' Forum which was a self-help group for carers of hospice patients which met bi-monthly at the hospice. Therefore the six carers who attended the Carers' Forum were identified by the Day Hospice manager as potential participants. This pool of people were judged to be most likely to agree to participate in the study on the grounds that they had already expressed an interest in carer issues and had been available to attend meetings of the Carers' Forum. The Hospice Community Nursing Team also approached 20 carers whom they judged likely to agree to participate in the research, but none agreed to take part in the study.

The patient and carer interviews were conducted in accordance with the principles of theoretical sampling, as the focus groups had been. Therefore, as soon as possible after transcription took place, each individual interview underwent initial analysis. The codes and early theoretical ideas which emerged informed how the next interview was conducted by suggesting the probing of certain putative codes and concepts which had been generated during the previous interview(s). Consequently, although each interview was conducted in a similar manner, the data collection via each successive interview was simultaneously part of the developing analysis. In this way, interviews continued on a cumulative basis, each being

informed by the analysis of the last, until saturation was reached after nine patient interviews and two carer interviews.

A day hospice administrator contacted 20 Day Hospice patients by post to invite them to have a 30-60 minute interview with the researcher to discuss their views on choosing a place for their death. The mailing contained an invitation letter (Appendix 1) and information sheet (Appendix 2) detailing the purpose of the research and the risks and benefits to the participants in taking part in the study. Patients replied directly to the researcher either by email or post via the stamped addressed envelope provided. Ten patients were recruited and ten failed to respond to the invitation. Nine face to face interviews took place as one patient became too ill to have her planned interview. However, during the period of the interviews this potential patient participant phoned the researcher to explain that she wanted to tell the researcher her views via a brief five minute phone call.

The following inclusion and exclusion criteria were used:

Inclusion criteria:

- Day hospice patients.

Exclusion criteria:

- In-patient unit patients. It was considered inappropriate to interview inpatient unit patients due to the sensitive nature of the topic of preferred place of death and at a time when death may be imminent for some patients. The inpatient unit is a clinical treatment area and it was decided that it would be inappropriate to conduct research whilst patients were receiving treatment which required a stay on the inpatient unit. In addition, inpatients may be too unwell to participate in such



research and it was considered highly doubtful that the hospice would have allowed access to these patients for this purpose.

- Day hospice patients who lacked the mental capacity to give informed consent were excluded. This information was recorded in the patients' admission notes and was available to the hospice administrator who made initial contact with potential patient participants.

Of the nine Day Hospice patients who had an interview, five chose to be interviewed in their own home and four were interviewed in the Day Hospice.

Figure 5.2 illustrates the demographic details of the patient participants and the location they chose for their interview.

**Figure 5.2 Demographic Details of Patient Participants**

<b>Participant</b>	<b>Gender</b>	<b>Age</b>	<b>Place of Interview</b>
Patient 1	Female	65	Home
Patient 2	Male	72	Home
Patient 3	Female	77	Home
Patient 4	Female	54	Hospice
Patient 5	Female	49	Home
Patient 6	Female	66	Hospice
Patient 7	Female	56	Hospice
Patient 8	Female	77	Hospice
Patient 9	Female	68	Hospice
Patient 10	Female	69	Via telephone

I conducted each 30-60 minute interview using The Interview Schedule (Appendix 7) to initiate and guide the discussion, but the participants were free to discuss any relevant subject areas arising from the conversation. Interviews were audio recorded and transcribed for analysis.

The patient interviews took place between February and April 2012. At the beginning of each interview I briefly explained that the purpose of this interview was to explore the participant's views on the topic of preferred place of death for hospice patients. The Research Participant Support Sheet (Appendix 5) was explained and given to the participant. Written consent was obtained via the signing of Consent Form Stage One (Appendix 3) and I pointed out that at the end of the interview the participant would be asked to sign a Consent Form Two (Appendix 4) to grant written permission for direct quotations of their words to be used in the research. I explained that the interview would last for no more than one hour and that the participant could ask to take a break or ask for the interview to be stopped at any time.

Having obtained permission to begin audio recording, I began with a few factual questions around age, ethnicity, family situation etc. before moving on to how the participant used the hospice and their thoughts on hospice care in general. The conversation was then guided towards the opening up of questions on death and dying and in particular their views on choosing a preferred place of death. At the end of the interview the participants were reminded about where to access further support if required and were asked to sign Consent Form Two regarding the usage of direct quotations. The interviews were later transcribed and analysed.

With regard to the one participant who was too ill to undertake an interview but

had a phone conversation with me, in the absence of the opportunity to audio record this phone call, I made notes on what was said. These notes were treated as a transcript.

A Day Hospice Administrator contacted the six carers who attended the Carers' Forum, following the same procedure as recruitment of patient participants. Two carers were recruited. The following inclusion and exclusion criteria were used:

Inclusion criteria:

- Primary adult carer of day hospice patient. The primary carer is defined as an unpaid adult (18+) who undertakes most of the informal care of the patient. This may be a spouse, partner, close friend or family member.

Exclusion criteria:

- Child relatives of day hospice patients
- Primary carers who are unable to give informed consent due to lack of capacity.

Of the two carers who had an interview, one chose to be interviewed at home and one in the Day Hospice. Figure 5.3 illustrates the demographic details of the patient participants and the location they chose for their interview.

**Figure 5.3 Demographic Details of Carer Participants**

<b>Participant</b>	<b>Gender</b>	<b>Age</b>	<b>Place of Interview</b>
Carer 1	Male	77	Home
Carer 2	Female	69	Hospice

### **5.6 Theoretical Sampling**

As this research study utilised constructivist grounded theory methodology, the essential consideration in determining the number of focus groups and patient and carer interviews was the concept of theoretical saturation. According to this concept, initial data is collected from which tentative analytic codes are developed, then further data is sought in order to corroborate or challenge these existing codes, to elaborate on their properties and theorise about potential interlinkages (Webb and Kevern, 2001). This process is known as theoretical sampling. Data collection ceases when theoretical categories are complete in that no new theoretical insights are forthcoming from the research participants (Thornberg and Charmaz, 2011). As each focus group and each interview underwent initial analysis immediately after it took place and tentative codes and categories were generated at this stage, the next focus group or interview was used to ask increasing focussed questions on the various aspects of the emerging theory, that is the tentative codes and categories (Charmaz, 2012).

Accordingly, the possibility of more than one focus group being required to reach theoretical saturation was always envisaged within the design of this research study. Similarly it was envisaged that a number of patient and carer interviews would be required, but the exact number of interviews was not decided at the start of this study. The decision to cease

sampling would be taken when it became evident to myself and supervisors that no new properties of the emerging categories were forthcoming and that compelling and robust data to support the emerging categories had been gathered (Charmaz, 2012).

With regard to the focus groups, due to concerns from members of the hospice management around how this research might encroach on day to day work of hospice staff, the number of focus groups had to be specified before the study began. It was felt that recruitment to more than two focus groups would not be feasible as attendance at focus groups could impinge adversely on the smooth running of the hospice day. The supervisory team, who were experienced in conducting focus groups, were confident that seeking the views of a pool of around twenty staff members via two focus groups would yield enough rich data to approach a satisfactory level of theoretical saturation. It is acknowledged that this pragmatic and realistic approach can appear to have limited the extent to which theoretical sampling was used. Nevertheless, had I felt that subsequent focus groups been required to reach saturation, I was prepared to approach the hospice to arrange this, but in fact, an acceptable level of saturation was reached after the two focus groups.

Several factors influenced the number of interviews conducted and the extent to which theoretical sampling was used. Regarding the number of patient interviews conducted, it is acknowledged that recruitment procedures played a part in determining the outcome. In particular, it is acknowledged that the action of the Day Hospice Manager constituted a certain degree of gatekeeping in effectively granting access to certain potential patient participants and denying access to others. It is reasonable to wonder whether different insights would have been accrued from a different group of participants. However, it was firmly held that there were no 'right' or 'wrong' patients to recruit to this constructivist

grounded study because every patient approached for recruitment was capable of providing rich qualitative data around the issue of PPD since each potential participant was living with a terminal diagnosis and a time-limited prognosis. Furthermore, all studies of this type are inevitably circumscribed by context and the particulars of those who choose to partake. In addition, the Day Hospice manager's judgement may have been correct in that certain patients were more likely to self-select into the study. It was judged that the intervention of the Day Hospice Manager did not adversely affect the study as a large enough sample was successfully recruited (nine patients) to achieve a satisfactory level of theoretical saturation.

The pool of six participants approached for carer interviews was smaller than originally envisaged as I had hoped to recruit a pool of around eight to 12 carers, to optimise the potential of achieving theoretical saturation. Therefore, it is acknowledged that the small number of participants recruited may have limited the extent of theoretical sampling with regard to carers. Nevertheless, as it proved to be impossible to recruit a larger group of carers within the desired timescale, in conjunction with supervisors, I decided to proceed with contacting the smaller group of carers and to re-assess the sample size requirements after the carer interviews had undergone initial analysis. In conjunction with supervisors it was decided that an adequate level of saturation had been reached after the two carer interviews, as the analysis of these interviews assisted in elaborating properties of emerging theoretical categories and furthering theory development.

## **5.7 Summary**

In summary, this chapter has described the methods and procedures which constituted the effective means of exploring PPD from the perspectives of hospice users and carers. Chapter six will describe the methods of data analysis.

## **Chapter Six            Methods of Data Analysis**

### **6.1    Introduction**

This chapter presents how the data was managed and processed. Firstly, grounded theory methods of data analysis are explained. Then specific techniques employed within this study, are described, including how coding processes and the constant comparative method were deployed. Finally, a description of the particular ways that analysis was carried out in this study is given.

### **6.2    Data Analysis within Grounded Theory**

The primary step in analysis in grounded theory, as in most qualitative research methods, is the generation of codes from the raw data. These codes, which are conceptual labels assigned to small portions of data, form the basic building blocks of theory construction. Strauss and Corbin (1990) describe coding in grounded theory as the operations by which data are broken down, conceptualised and eventually put back together in theoretical form. Charmaz (2011) outlines two main types of coding: initial line-by-line coding and focussed coding.

In line-by-line coding each line or portion of data is given a label whose function is not merely to précis the data, nor yet to pick out some dominant themes, but to achieve a certain level of abstraction (Walker, Read and Priest, 2013b). Conceptual abstraction has been described as directing attention to and isolating a part or aspect of an entity or phenomenon for the purposes of contemplation (Whitehead, 1925). This means that each code must contain the power not merely to describe, but to begin to explain what the data related. Thus, the very first steps of working with the data in this study, that is the focus groups transcripts, provided the means of thinking about a theoretical explanation of the

social forces at play in the lives of the research participants within their social context (Holton, 2007).

Charmaz's second type of coding, focussed coding, entails sorting and synthesising the line-by-line codes into smaller, more selective units at a higher level of abstraction. Focussed coding is guided by emerging analytical directions detected in the line-by-line coding stage and involves decision making around which line-by-line codes are the most appropriate to analyse the data effectively.

Based on analytic directions and inspirations growing out of the coding, the research is further progressed by memo-writing to explicate emerging theoretical ideas. Lempert (2007) defines memos as the narrated records of a theorist's analytical conversations with him/herself about the research data. Their use is recommended at every level of research as an aid to ensuring that possible analytic directions and ideas are not omitted. Stern (2007) considers memo writing to be essential because of the tendency of unwritten theorising to waft away and be lost to the eventual theory. An example of one memo, free-written, about the tentative category Power is given in Figure 6.5

Memos may be developed into categories, whose properties are specified and explicated until theoretical saturation is reached whereby no new properties of the category appear in the data. Theoretical categories are eventually integrated to form the grounded theory which can offer a conceptual explanation of the latent pattern of behaviour with the social setting of the study (Holton, 2007).



### **6.3 Managing the Data**

I had considered using a computer software programme to assist with managing the data analysis, but, in agreement with Glaser, I found such a system too constraining and burdensome (Glaser, 2005), and incompatible with capturing my own ways of thinking creatively and analytically about the data. Therefore all coding was carried out by hand with the various sheets of paper collated in a Data Analysis Box Folder.

With regard to initial line-by-line coding, working with a paper copy of each transcript, I hand-wrote a code above each line and noted other ideas about the data in the margin. Keywords, phrases, themes or other ideas about each transcript were written on a separate large sheet of paper. This was added to after each transcript had been line-by-line coded, resulting in the compilation of a large number of, initially, unconnected words about the transcripts, which could be used to progress further analytic thinking in terms of refining the line-by-line codes or suggesting analysis at a higher level of abstraction. Similar creative thinking was also done manually in the form of lists, spider diagrams and mind-maps.

After the line-by-line coding was completed, focussed codes were developed at the next level of conceptual abstraction. In addition to recording the focussed codes in lists and diagrams, I returned to the transcripts and used different colours to highlight sections from which the focussed codes had developed. This is illustrated in Figure 6.1.

Returning to the raw data in this way served as a means of keeping the developing theory well-grounded and illustrates how the constant comparison of the different levels of data analysis drove the generation of this grounded theory (Birks and Mills, 2011).

Figure 6.1 – Focus Group 2 Extract of Hand-written Coding of A Transcript

Extract Focus Group 2 Transcript  
Line-by-line coding

14 Describing pat's decision making  
"I've changed my mind and and I've recognised that perhaps going home

15 wouldn't be the place for me." So that's just some of you know one

16 experience that that I've had

17 3. P That's pretty typical in a community setting that you perhaps have

skills 18 Describing documentation  
done the Supportive Care Plan, discuss it at the Gold Standards

19 Framework meetings and discuss it primarily with the patient, speak to

20 Trying to support pat choice  
the family and support the wishes regarding what they're saying, but

21 when the crisis happens there isn't always 24 hour care in the community

service prov 22 Limits of service provision  
and it isn't always possible to fulfill the wishes or sometimes the carer's

23 Noticing differences in pat/family wishes  
wishes and the patient's wishes are very different  
pat auton family influence carer family pat wishes

24 4. P I guess that's a good point isn't it about the patient's wishes and

25 Family's influence on PPD  
the carer's wishes and how they can be quite different and then you're

self awareness 26 Staff as mediator  
you're sort of left with this dilemma of sort of wanting to address the

27 wanting to promote autonomy  
wishes of the patients but it conflicts so much with the relatives and what

28 Family issues re care  
support support the relatives can give to the patients family

29 5. M A few nods going round the room here. Is that that familiar to

30 people?

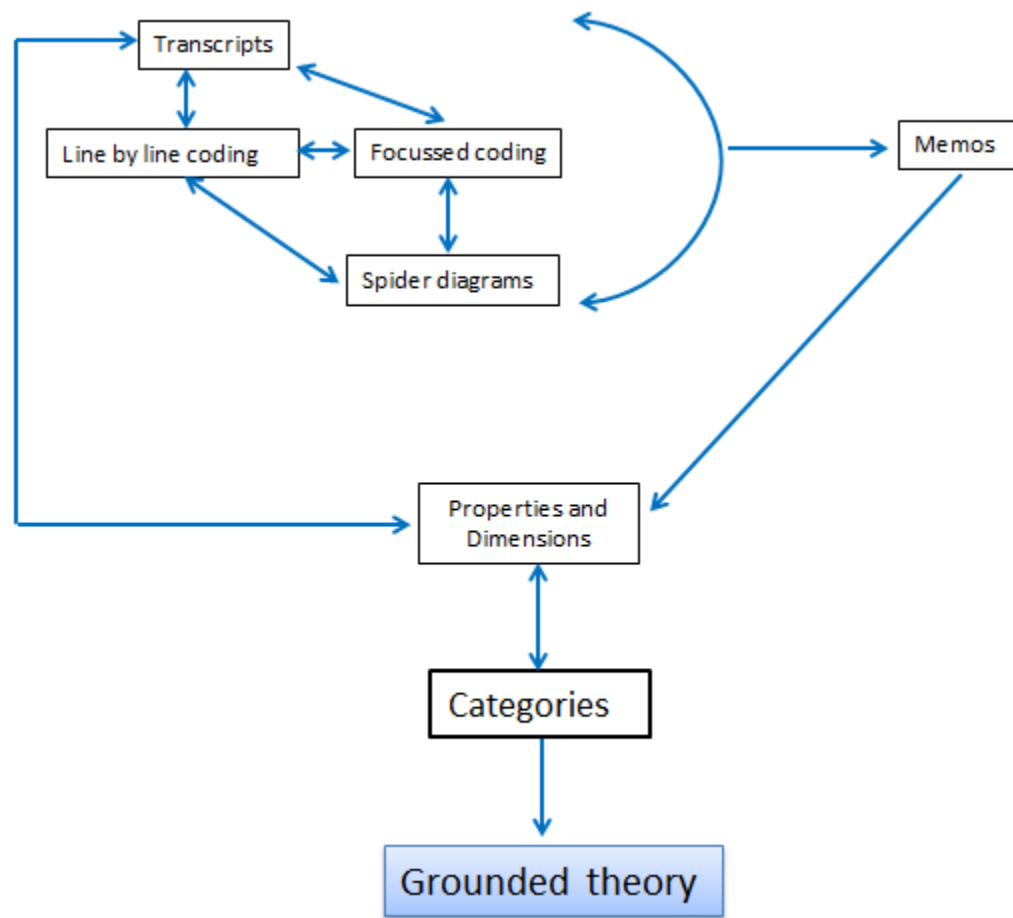
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In a similar way, at any time during the analysis, memos were generated. These were either hand-written or type-written. Some of the memos were developed into categories by returning to data to search for properties of that conceptual category. Corbin and Strauss (1998) define a property as a characteristic of a category which when delineated gives the category meaning. So, by close study of the data each category was delineated or explicated in terms of its properties or characteristics. This again shows constant comparative method and 'groundedness' of this theory. The explication of the categories was recorded via type-written text and diagrams.

I then assembled all the different categories onto one sheet of paper to begin thinking about the next level of conceptual abstraction. This comprised considering how the different categories fitted together to create a complete picture of the hospice experience of PPD and considering what the core category might be, around which the grounded theory would cohere.

In these ways the data was managed and constantly compared as the analysis moved onwards. This constant comparative method practised is illustrated in Figure 6.2

**Figure 6.2 Constant Comparative Analysis in This Study**



#### **6.4 Processing the Data**

The particular ways in which the data from the focus groups, patient interviews and carer interviews were processed are now described.

I transcribed and initial line-by-line coded the audio recording of the first focus group. At this early stage in the analysis, I found the process of generating codes with conceptual power something of a hurdle in that some of my line-by-line codes were more descriptive than conceptual. I discovered that writing in a reflective research diary helped me to determine

and reflect on certain particular difficulties I was facing. The diary reports that a sufficient level of conceptual abstraction was not always easily achieved as it was sometimes difficult to decide whether an assigned label erred towards description rather than abstraction and I found that very often I changed original codes to what felt like a more satisfactory term. For example, the diary records my ruminations over how to code one participant's expressed desire not to die at home. This participant said that even though she loved her own bed, she did not wish to die in it as *it would be a waste of a bloody good bed*. This remark was originally coded as *Using Humour to Talk about PPD*, but this felt too descriptive so I later changed the code to *Considering Practicalities of PPD*.

Therefore, I continued to work at the line-by-line codes to ensure they achieved a certain level of abstraction. Figure 6.3 gives an example of the original line-by-line codes, which were quite descriptive, being developed into more conceptual codes.

**Figure 6.3 Early Development of Line by Line Codes**

<b>Original descriptive line-by-line code</b>	<b>Revised conceptual line-by-line code</b>
Patient says can't cope at home	Listening to what patients want
Do staff ask their wishes?	Listening to what patients want
Family say they can't go home	Aiding communication within family
Patients says they want to go home	Aiding communication with family

When satisfied that the line-by-line coding of focus group one had achieved a sufficient level of abstraction, I moved on the next level of abstraction, that is focussed coding. In the

research diary, I noted that, again, it was quite difficult to move beyond the line-by-line coding stage and towards the next level of abstraction. The following excerpt captures the tenor of my thinking at the time when I sat down to begin focussed coding:

*So now what? I've spent ages generating all these codes, transcribing, listening and listening again to the participants' voices, trying hard to capture what **they** wanted to say, so how do I get it into bite-sized chunks without missing something vital out?*

This extract frankly demonstrates that questions around the sorting and synthesising of line-by-line codes felt like a substantial challenge. In particular it raised questions about whether focussed coding would require a form of editing in terms of making cuts to certain codes: that is losing them from the progressing analysis, or whether all line-by-line codes were to be somehow subsumed into the next level of abstraction. It also drew attention to the relationship between the process of subsuming codes through greater abstractions and the potential loss of detail and meaning captured in the original line-by-line codes.

At this point in the study, the diary attempts to strike an encouraging note in referencing Charmaz' (2011) notion of grounded theory as a craft that researchers practice, and the touching faith of my supervisors that focussed coding was well within my capabilities. Therefore, I decided to simply become immersed in the focussed coding and to continue to reflect on how and why I was making decisions about handling the data at this stage.

At a time when I was struggling to progress the coding, the diary records a moment of "breakthrough" when I began to conceive of the need to engage in a kind of deep and attentive listening to the line-by-line codes. Building on this idea of listening to the codes,

the notion of *codes' voices* began to develop. If each code had a voice with something of significance to say, then the process of focussed coding could be seen as one of translation. Translation is concerned with transferring a message from one language into another and, crucially, expressing the sense of the original communication in other words (Little Oxford English Dictionary, 1976). Expressing the sense of the original communication or translating the codes' voices seemed to allow focussed coding to render concepts which remained true to the original data. For example the in vivo code "*there's no persuasion*" was translated, and, it may be argued, encapsulated, in the focussed code *Decision Making Regarding PPD*. Similarly, the line-by-line code *Glad to Talk* was translated into the focussed code of *Reflecting on Exploring PPD*.

In addition to deep and attentive listening to the line-by-line codes, I arrived at the focussed codes by way of cluster lists. This involved noting which line-by-line codes were repeated most frequently, then re-arranging them in loosely grouped lists handwritten on a large sheet of paper. I found that this visual notation was helpful because it soon became possible to see discrete groups or clusters forming around an emerging theme. For example, as the following cluster list began to form, an encompassing theme of *Issues in Talking with the Family* began to suggest itself in my mind. This encompassing theme became the focussed code. The cluster list reads as follows:

- family reaction to talking about PPD;
- family denial of oncoming death;
- family difficulty in talking;
- family reluctance to talk; and
- family openness to talking.

It is evident from the reflective diary that at this stage of the study I was clearly learning to manipulate methodology of grounded theory analysis as I went along and the diary provided a space in which to think out loud as shown by the following note on cluster lists:

*Now try linking/re-ordering cluster lists. Make sure the conceptual power of these focussed codes and their relationships to the data is maintained and demonstrated by signposting to examples of line-by-line codes from which each focus code has grown.*

Using the cluster list method, I succeeded in generating a number of focussed codes, which I noted in a table and discussed with the second moderator/ PhD supervisor. The second moderator had also coded the transcript and had produced a spider diagram depicting line-by-line codes in relationship to focussed codes which possessed a higher level of abstraction. The heading of this spider diagram was "*Death Never Occurs in a Vacuum but in a Social Context*" (Read, 2011). In addition to suggesting itself as a useful title for a memo, this overarching theme was a helpful means of re-iterating that the purpose of the focus groups was not merely to present a description of what hospice staff had to say on this matter, but moreover to theorise about the social processes involved in PPD for hospice staff.

In this way nine focussed codes were developed from Focus Group One. These were:



- Promoting Patient autonomy
- Family dynamics
- Service provision concerns
- Medical factors
- Learning and skills
- Communication
- Time Factor
- Documentation
- Staff self-awareness

Several ideas for memos suggested themselves from this focussed coding process, which provided a means of further tentative analytical thinking about the research. For example, from the focussed code *Supporting Patient Autonomy* came the idea for writing a memo on *Autonomy* and one entitled *Enabling the Patient Voice*. The focussed code *Communication* provoked a memo on *Mediation*. The title of the second moderator's spider diagram *Death Never Occurs in a Vacuum* led to thinking about the importance of context in this study.

At this stage the memos which had been generated were all regarded as potential categories or sub-categories which would require developing in terms of their properties. This was undertaken in a preliminary manner at this point. According to grounded theory principles of theoretical sampling, to further explicate the properties of the tentative categories, it was appropriate to gather more data from a second hospice staff focus group. The Second Focus Group participants would be offered the same focus group schedule basic questions with

particular attention to the tentative theoretical ideas generated in Focus Group One in order to determine whether or not these ideas would be supported, challenged or elaborated.

As with the first focus group, I transcribed and line-by-line coded the audio recording of the second focus group. Some loose cluster lists and potential focus codes were also generated. This coding work was then discussed with the second moderator/PhD supervisor. The nine focussed codes from Focus Group One were largely supported by the coding of Focus Group Two with some amendments.

Firstly the validity of proposing the following focussed codes as discrete codes was challenged:

- Staff Self Awareness
- Learning and Skills
- Time Factor

Much of the data presented under the headings of *Staff Self-Awareness* and *Learning and Skills* were directly related to the concept of *Communication* and thus could be usefully subsumed by the focussed code of *Communication*. Secondly it was agreed that the focussed code of *Time Factor* was not robust enough to stand on its own and would be better interpreted as part of the focussed code of *Service Provision*. To test out the emerging theoretical ideas and determine whether saturation had been reached, the data was considered in its entirety. The one big theme was: *Hospice Staff Trying to Help Patients Achieve PPD*. I recognised that this theme was threaded through both Focus Group Codes, but this did not yet represent an organising abstract principle; it was still an observation at

the descriptive level. A second question suggested itself which led to a more problematising approach: What social processes are impacting on the hospice staff's attempts to help patients achieve PPD? The data was then re-examined through the lens of this question. Therefore, looking across all the data, with the above question in mind, the remaining 6 focussed codes were considered robust enough to stand as theoretically relevant. These were:

- Promoting Patient Autonomy
- Family Issues
- Service Provision
- Communication
- Documentation
- Medical Factors

The reflective research diary records this moment being characterised by the second moderator as "an ah-ha moment".

In these ways the Phase Two Hospice Staff Focus Groups produced valuable data on which to begin the first tentative steps towards grounded theory building. This included the generation of six focussed codes, several memos and a number of reflective observations which were noted in the reflective research diary. These early analytic ideas were then further tested in terms of saturation with data from patient interviews and carer interviews.

I transcribed the audio recordings of each of the nine patient interviews and two carer interviews as soon as possible after each interview had taken place. Notes which I took from the telephone interview with a patient participant were also treated as a patient interview

transcript. Each interview was line-by-line coded, and initial ideas about focussed coding were noted. If any potential memos came to mind at that stage, they were also noted. Then the next interview was conducted. This allowed for emerging ideas about analysis of interview data to inform the conducting of the subsequent interview, just as the emerging focus group analysis had informed the patient and carer interviews.

When line-by-line and initial focussed coding of all the interviews, had been conducted, all the transcripts (including focus groups) were re-visited en bloc to examine whether more focussed coding work was necessary. Looking across all the data, focussed codes which were repeated most frequently were recorded in loosely grouped lists handwritten on a large sheet of paper, in a similar way to how the cluster lists of line-by-line codes had been produced. Again this type of visual notation was helpful because it soon became possible to see discrete groups of focussed codes emerging. Some focussed codes were linked with others as they seemed to be part of the same concept e.g. the focussed code *Decision Making Regarding PPD* subsumed the two codes of *Giving Reasons for PPD* and *Making Choices about PPD*. In this way, nine focussed codes were generated from the patient and carer interview transcripts. The conceptual power of these focussed codes and their relationships to the data was maintained and demonstrated by signposting to examples of line-by-line codes from which each focus code had grown as shown in figure 6.4

**Figure 6.4 Example of the Development of Focussed Codes**

<b>Focussed Code</b>	<b>Cluster List</b>	<b>Line-by-line Code</b>
Issues in talking with family	Family reaction Family denial of death Family difficulty in talking Family reluctance to talk Family openness to talking	Not taboo P1:172; Upset P4:149 Husband's denial P8:44 Too hard P5:105; P2:268
Decision making regarding PPD	Giving reasons for choice  Making choices  Stating PPD Thinking about PPD	Husband willing but upset P5:104; Children reluctant P7:90 Supportive daughter P9:108; Everyday conversation P1:174 Not home P2:213; 'Don't want to be carried out in a body bag'; P7:146; P4:193 Not hospital P6:195; P5:340 Privacy & Confidence in Hospice P4:171; Concerns re symptoms P3:114; P4:229 Considering options P3:2; P2:215; P3:2; P1:163; P10:2; P8:59 Existing view P1:161; P4:304; P5:356 Not wanting to think P2:128

Re-visiting the focussed coding en bloc in this way and making decisions around what the codes conveyed conceptually, led to a measure of theorising around the social processes impinging on the lives of the participants. Such theoretical ideas were recorded in memo form. An example of one memo, free-written, about the tentative category Power is given in Figure 6.5

**Figure 6.5 Extract from a Memo on Power**

**Power as an interlinking thread**

As this process of focussed coding goes on I sense a connecting thread emerging between the codes, but am struggling to discern the nature and indeed the name of this thread. Try the following question: *Through the process of looking at PPD and engaging with PPD did anything change for the patients?* In many of the codes I sense that the patients gained power

- power of new knowledge
- power to discuss issues around death
- power to choose to record their PPD or not
- power to express their views about doing this.

Can I therefore postulate the notion of empowerment as a conceptual thread linking codes. This seems a big conceptual jump, needing testing in the data: is the concept of empowerment validly and groundedly found in the data, is it a link between codes and will it be a useful handle in making sense of data?

Strauss and Corbin (1990) talk about this part of the process of GT as verification of statements against data whereby the researcher returns to the data to look for evidence that supports or refutes the assertions, in this case that empowerment is a conceptual link between codes.

**What is power?**

What is power as a social force/construct and what does having it or not having it mean? "We've got the power!" "Power to the people!" Why do people want/need power in society? Power = the ability to make things happen: to cause or prevent actions. It can also be the ability to influence the behaviour and actions of others.

Thus it is enabling. It allows one to do things and is connected to taking control. What

does it feel like to be powerless? You cannot decide for yourself what will happen to you; you may need to ask permission of others or you may need to ask others to assist you. It's about having no control over what will happen. This has resonances with ability and disability, wellness and illness. My years of experience as a hospice chaplain confirms that people who are ill often describe a sense of loss of power that comes with illness. They can no longer do the things they used to such as their job, taking care of the children in the same way, shopping and cooking for themselves and this is often a negative experience. They cannot do the things they would want to do: there is now a lack of choice as they must do what others tell them. They are constrained by the limitations of their illness. For some this can have serious psychological and emotional distress and even those who come to some kind of psychological accommodation with illness often report feelings of grief and loss. Constraint versus enablement – related to authority and social structures (think I did this in Machiavelli, as a history undergrad?) Choice versus no choice. So is being offered choice in PPD a potential power issue? Is this a way by which dying people can exercise some power/control over their own destiny? Is this the last chance they will get to be empowered? How will this affect their significant relationships e.g. family and professional carers, that is hospice staff. What of balance of power in these relationships?

One of the original questions in the PhD proposal was around the power relationships in the health service. Are consumers (patients, informal carers) seen as passive recipients of care and treatment or as partners exercising agency within their healthcare experience. How do consumers perceive themselves and how are they perceived by those with a duty of care towards them?

Other brief memos were also generated arising from the many line-by-line codes which were generated by the seemingly extraneous, irrelevant and somewhat banal biographical details which were recorded at the beginning of an interview. The intention in these memos was not to theorise about emerging concepts, but, rather to ensure that the voice of the lifeworld of each participant was neither ignored nor excised. These memos then, served to inform the analysis and thus add depth and richness to the developing picture of the social process at work in the lives of the patients. They were not developed into categories but aided and enriched my analytic thinking. Figure 6.6 gives an example of such a memo.

**Figure 6.6 Memo on Patient Nine Interview: Family**

<p><b>Biographical Detail: What does it say about the participant's experience and <i>lifeworld</i>?</b></p> <p>What in many ways characterised this interview was that this patient participant had lots to say about her family. Yes, this may be extraneous to the research question, but it is very revealing about the participant. She told me about:</p> <ul style="list-style-type: none"><li>• One grandson's recent move to Australia with details of his job and accommodation</li><li>• The other grandson's near fatal accident two years ago with details of his medical treatment and progress towards recovery</li><li>• Her husband's diagnosis of serious illness and the details of his treatment</li><li>• Her daughter's struggles with her mother's diagnosis and helpful interventions she (daughter) had experienced</li><li>• The details of who, in the family, has power of attorney.</li></ul> <p>All of the above says to me that this is a very close family who share many details of each other's lives and who support each other through illness and difficulty.</p>
--



The focussed coding work and memos were then reviewed in collaboration with the two PhD supervisors. It was agreed to attempt to develop twelve memos into potential categories. For example, the category *Power to Engage with PPD* was explicated by the properties of: *Talking about End of Life Care*; *Considering Plans for End of Life Care* and *Communicating Wishes Regarding End of Life*. Each property was then considered in terms of the range of variance which was demonstrated by the property. For example the range of variance for talking about end of life care was from the general to the specific.

When the categories had been elaborated in these ways, they would possess density and precision and would therefore be able to contribute to the conceptual depth and breadth of the grounded theory. These potential categories were subsequently reviewed collaboratively and it was agreed that seven had been robustly explicated and that four should be subsumed into other categories. Thus *Communication Breakdown* was subsumed into *Communication*; *Negotiation* was subsumed into *Mediation* and both *Patient and Carer Issues* and *Participant Lifeworld* were subsumed into *Patient Autonomy*. It was agreed that the potential category of *Social Context of Death* was not robust enough to stand as a category, but was, nevertheless, an important concept which would inform the understanding of the social setting of the research. Figure 6.7 illustrates how the twelve memos were developed into seven categories.

**Figure 6.7 Development of the Seven Categories**

<b>The Twelve Memos</b>	<b>The Seven Categories</b>
Autonomy	Patient Autonomy
Barriers and Access	Barriers and Access
Enabling the Patient Voice	Enabling the Patient Voice
Power	Power to engage with PPD
Communication	Communication as Empowerment
Communication Breakdown	Safe Space to engage with PPD
Creating a Safe Space	Mediation
Mediation	
Negotiation	
Social Context of Death	
Patient and Carer Issues	
Participant Lifeworld	

The relationships between these seven categories in terms of depicting a theoretical interpretation of the data were then discussed with my supervisors and the core category was selected.

## **6.5 Summary**

This chapter has described how the data was progressed towards an analytic understanding. This foundational work provided the building blocks with which a constructivist grounded theory was generated. Chapter Seven will present the Core Category.

## **Chapter Seven      The Core Category**

### **7.1      Introduction**

This chapter presents the core category of this grounded theory that is, 'Enabling the Patient Voice to be Heard'. An explanation of what is meant by the conceptual term 'Enabling The Patient Voice to be Heard' is given. The social processes at work within the concept of 'Enabling The Patient Voice to be Heard' are then set out and the term 'Components of Enabling the Patient Voice to Be Heard' is clarified. The components of enabling in terms of tools and skills; opportunity to speak; permission to speak and support available are then presented and explicated. The range of conditions under which each component operates is illustrated and the usage of the term 'influences on' is explained and details of its deployment are presented.

### **7.2      The Conceptual Term 'Enabling The Patient Voice to be Heard'**

The notion of enabling is linked with helping and empowerment: giving power to someone so that they can do something for themselves. A useful example of the process of empowerment at work in society is the anti-discriminatory practice development in the UK in the 20th and early 21st centuries. It is no exaggeration to describe changing societal views, attitudes and treatment of people with disabilities as having undergone something of a revolution in recent years. For example enshrining of positive views of people with disabilities in The Equality Act (2010), and providing widespread anti-discriminatory education aimed at providing a more positive view of people with disabilities, puts people, rather than disabilities at the centre of the debate.

Furthermore, new understandings of old words, which may be offensive to some, such as "handicapped" and "invalid" have been replaced to show how matters of social justice were

intrinsically caught up with and sometimes subtly hidden within their accepted meanings. It is now widely accepted that whilst people may be disabled, it is society's perceptions and values which handicaps people by the barriers it erects which prevent people with disabilities from accessing goods and services that are freely available to non-disabled people.

Examples of such barriers might be stairs to people with impaired mobility; unnecessarily lengthy and wordy documents to people with learning disabilities and attitudes based on prejudices and stereotypes to people with mental health issues or hidden disabilities.

In the case of disability issues, it may be argued that the process of enabling or empowerment has resulted in significant changes in the lives of individuals and in society at large, as society has been challenged to re-evaluate its apparently given ways of treatment of and attitudes towards people with disabilities. Enabling, then, is a powerful notion.

'Enabling The Patient Voice to be Heard' is the conceptual term employed to denote what happens when the hospice patients, carers and staff interact with the phenomenon of PPD. The data amassed from staff focus groups and patient and carer interviews suggested that ascertaining and recording a patient's PPD acted as a means of enabling patients to voice their views and for these views to be heard. For some patients and carers this would involve engaging in a discussion of the issues involved with a member of staff, whilst for others this would involve exercising their right to decline such a conversation or at least postpone it. Societal norms and mores around talking about death would be part of this negotiation for all involved: hospice staff, patients and carers. In a society which has in recent times made death something of a taboo subject and has rather embraced the model of death as medical failure, it is perhaps not surprising that conversations concerning the details of a person's death need enablement.

'Enabling patients' voices to be heard', then, implies the need to help people to be heard who have not been heard before. Conversely, disabling patients' voices would involve preventing patients from voicing their views. The question of whether hospice systems were intentionally or unwittingly conspiring to aid or prevent patients' voices from being heard is a pertinent one. Patients largely reported that until hospice staff offered them the opportunity to record their end of life care wishes and preferences via the hospice notes, they had not previously been asked to express their views on this topic. No other healthcare professional had asked them where they wanted to die, their family members had not asked them and it could be argued that society at large had not required this. For example, there is no legal requirement or incentive to log one's end of life wishes.

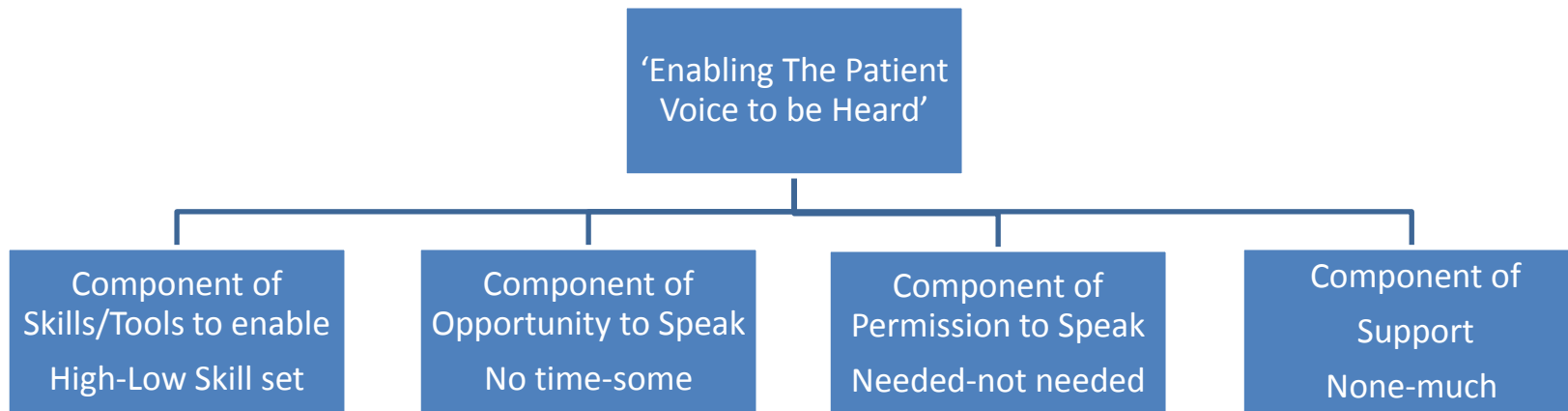
The increasing trend for the purchasing of pre-paid funerals, which allows a measure of control over end of life matters, is one of the few indicators that perhaps UK society is becoming more aware of opportunities to make plans for the end of life. Funerals, however, occur post-death whereas this research is concerned with planning in advance for the place of death. Some patients reported their erstwhile reluctance to consider this topic, whilst others had been actively discouraged from doing so by well-meaning family members. Actively engaging in the process of recording the patient's PPD, then, may be seen as a method of 'Enabling the Patient's Voice to be Heard'.

### **7.3 Social Processes at Work as PPD is Explored**

The data showed that there were a number of different ways in which 'Enabling the Patient Voice to be Heard' was experienced. A number of social processes were at work as PPD was explored. These processes are viewed as 'Components of Enabling The Patient Voice to be Heard' and are defined as Tools and Skills; Opportunity; and Permission and Support.

To depict the conceptual understanding of how these components functioned both as social processes and as integral parts of this key category of 'Enabling the Patient Voice to be Heard', the diagram given in Figure 7.1 was generated. Each component is considered in terms of its dimensions or the range of variance demonstrated by the component and the conditions under which it operated. For example the component Opportunity to Speak is mediated by the range of having no time to having some time in which to do this. This kind of diagrammatic thinking was a useful tool for discovering and developing the mechanisms of enablement which were present in the data.

Figure 7.1 'Enabling The Patient Voice to be Heard'



## **7.4 Components of 'Enabling The Patient Voice to be Heard'**

### **7.4.1 Tools and Skills**

One component in 'Enabling the Patient Voice to be Heard' relates to the acquisition and availability of tools and skills to assist in the facilitation of the voicing of views. Patients, carers and staff members possessed a variety of tools and skills around end of life issues. The level of skills possessed by individuals varied along a continuum. Some skills were longitudinal in the sense that they resided within the institution of the hospice and could be made available when necessary, rather as money resides in a bank and can be withdrawn as funds when required. Other skills were more transient in that they were activated as a response to a moment in time, such as an unplanned conversation on the topic of PPD.

### **7.4.2 Opportunities to Speak**

This component concerns how opportunities to speak about PPD were made available to patients and how patients made use of such opportunities. The active creation of opportunities for patients to speak is an important concept because the realisation of ambition is not always predicated on the mere possession of ability and desire. For example I may have the physical ability to swim the English Channel and it may be my deepest wish to achieve this goal, but if I have neither time to train nor time to perform the feat, I will never succeed in my ambition. In a similar way, the patient may wish to speak to someone about their PPD and they may be perfectly capable of articulating their thoughts on the issue, but there must be at least one occasion when this is made possible. For many patients, this opportunity was created when staff raised the topic with them, often in response to attempting to record the patient's wishes in the hospice casenotes.



Time was an important factor as patients' experiences varied from having no time to take advantage of such an opportunity to finding some time to speak. This in turn was dependent either partly or wholly upon the individual's life story and the trajectory and rapidity of their illness progression. Additionally, taking the opportunity to speak about this issue was a recurrent activity for some whilst others availed themselves of this facility for one time only.

#### **7.4.3 Permission to Speak**

This component refers to whether the patient felt constrained to any degree about voicing their views on PPD. It begs the question: Constrained by whom or what? Some patients did feel hindered by their family's view on this, or by their own perception of what is acceptable in society or even within the hospice, whilst some exercised their right to decline the opportunity to speak about PPD. Needing to gain permission to speak may imply that one has been required to keep silence hitherto. This touches on the power dynamics at play in this social situation and whether the patient has any power. Not all patients felt they needed to seek permission to speak; some were supported by those around them, but some clearly looked to the hospice staff to fulfil this role, whilst others experienced particular moments of empowerment through conversations on this issue with fellow patients.

#### **7.4.4 Support**

This component refers to how much backing was evidenced and experienced as patients attempted to voice their thoughts. Some support was structural; for example, documentation on PPD provided a place for the patient's voice to be recorded. The mere existence of a hospice, an institution dedicated to the care of terminally ill people, is in itself a form of structural support. Other support was accessed through encounters with hospice staff, family members, fellow patients and societal norms and trends. How much support patients

required or made use of varied from none at all to a great deal. For some, support was ongoing and so longitudinal in nature whereas for others it happened in a single event.

## **7.5 The Range of Conditions or 'Influences On' the Components**

As illustrated in the Figure 9.1, each component operated under a range of conditions which were engaged in to varying degrees by the participants. The term used to denote this range of conditions is 'Influences On'. The particular issues which acted as influences on these components are discussed in detail below with reference to the data.

### **7.5.1 Influences on Tools and Skills**

#### **Staff training**

There was no standardisation here nor uniformity; a factor which may influence how and if patients accessed the tools and skills to speak about their PPD. Some staff members had undergone training courses on communication skills and on breaking bad news, which they had found helpful and empowering, although none cited courses which dealt specifically with documenting PPD.

*It comes into the palliative care certificate... only briefly.. not you know,  
only .... how you deal with it, how you cope with patients and choice.  
That's as far as it went really. (Focus Group 2:203-205).*

Others felt they had learnt much from informal training which occurred "on the job" through working with experienced and highly skilled colleagues:

*I gained a lot from a previous doctor here.... Quite often he would have that conversation on the day of admission.....and then he'd come out with the conversation about where they'd want to be... he just sort of had a way... I personally learnt a lot through him. (Focus Group 1:459)*

### **Deployment of skills**

The level at which skills were deployed by hospice staff could have a significant impact on whether or not patients were enabled to speak and be heard on this issue. Examples were cited whereby healthcare professionals had omitted to ask the patient about their PPD and had made decisions about their care without taking into account the patient's wishes. An example was given of a female patient who was sent into the hospice for end of life care by a GP wishing to find the best care for their patient. A hospice doctor recounted the conversation he had had with this patient in which the patient said:

*I'm the last of 14 children born to my parents, doctor, all the, all my siblings have been born and dead in the same house and my only wish is to die in the same house. (Focus Group 1:115-118).*

This was an obvious source of frustration for some hospice staff members:

*Why couldn't we just ask this question to her? But by then it was too late... I'm not saying this happens very often but a lot of people forget to ask the basic question itself, what ... your wishes are. (Focus Group1: 118-120).*

Conversely, several patients reported encounters in which various healthcare professionals had deployed their skills in this area to good effect in that they had enabled the patient to understand the issues around making decision around PPD and had enabled them to voice their views. The following extract from a patient's transcript illustrates how a staff member explained and clarified the process with the patient and thereby supported them in their decision making:

*And part of the form I wasn't sure what to put.. so one of the er... I think it was (name of nurse) went through it with me so she explained which was better than just filling the form in yourself...at least parts... I mean some was easy, but some parts you think "Well you know what do I put there?" I think, so that was helpful, yeah. (Patient 8:167-170)*

Another patient recalled how her GP had asked her about her PPD and how she had found that helpful.

*I went to see the doctor just when I'd been diagnosed with cancer and he says to me "I've got to ask you this (patient's name), er where would you like to go if you die?" And he said "Would you go (name of hospice)?" and I said "Yes" and he said er you know "Do you want to be resuscitated?", I Said "No". And that's how it all come about... (Patient 6:145-148)*  
*He was very good about it, you know .... I felt... well relief cos I'd got somewhere (to) go. Patient 6:185 &187)*

These varied experiences regarding this demonstrated a range of levels of deployment of skills on the part of staff. Having access to staff skills could affect the process of enabling the patient voice being heard to a greater or lesser degree.

### **Awareness of Documentation**

The various levels of awareness of the existence of documentation in which to record patients' wishes also influenced the process of utilising skills and tools to 'Enable the Patient Voice to be Heard'. This applied to both patients and hospice staff. Patients found that the documentation prompted their thinking about the place where they might like to die and for some this was the first time they had considered this issue:

*It wasn't until I was approached at the hospice that I'd ever thought about er the er preferred place of dying. ((pause). I mean you er tend to think you'd like to die at home.....but in my own home it wouldn't be very practical (Patient 3:93-95)*

Some patients welcomed the opportunities that emerged from being made aware of this documentation: the opportunity to think about and articulate their wishes, to discuss this with a healthcare professional and with family and friends. Other patients found this less positive and some patients experienced learning about such documentation as a rather shocking experience:

*Well at first I just stopped in me.... cos nurse (name) explained it and I just stopped in me track. Cos it.. well you've got let it sink in.....yeah.. cos when nurse (name) had done the form and 'er says do you want me to sign it well I hung back and I just you know couldn't get me head round it proper. (Patient 3:142-144 &151-152)*

Staff knowledge about documentation currently available to support the ascertaining, documenting and reviewing of the patients PPD, could have a very direct impact on the process of 'Enabling the Patient Voice to be Heard'. During the course of this study the hospice in conjunction with the local hospital and Primary Care Trust had devised its own end of life care wishes document known as the Supportive Care Plan: Supporting Your Choices and Priorities in Advancing Illness. Helping You to Prepare for **Your** Future Care. The purpose of this document is described as being a method to:

- Establish the patient's wishes regarding their current and future care
- Enable the patient to be treated in the setting of their choice as far as is possible
- Act as a trigger for appropriate referral to other services
- Enable anticipatory planning of future care and provide a method to communicate these plans to other healthcare professionals.

There are sections dealing with medical history, patient/carer insight and understanding of the illness and future planning in addition to mechanisms for sharing information across the care team within the local health economy. This plan is filled in by a healthcare professional in conjunction with the patient and is signed by the patient, the healthcare professional who has completed the form and either the patient's consultant or GP. Triggers which could alert healthcare professionals as to the appropriate time to use this form include when curative treatment is no longer possible or has been declined by the patient or if the patient has been entered onto a community Gold Standards Framework Register (a Primary Care Trust mechanism for recording the preferred place of care for patients considered to be in their last year of life, NHS, 2001). Once completed, a copy of the Supportive Care Plan is given to

the patient and sent to all relevant healthcare professionals including the patient's GP, with the patient's consent.

Many staff felt that having the Supportive Care Plan was changing the landscape of end of life care planning in a positive way in that it enabled more open and sometimes deeper discussion about the patient experience.

*And sometimes in the community once, you know what I mean, once a patient sort of expresses a preferred place that can open up a lot of discussions... Such as about... what their fears are, now we can talk about other services and a lot of the time what they do fear is managing symptoms... (Focus Group 1:133-137)*

Some hospice staff noted the positive effect of the fact that this plan could be initiated by anyone in the care team, with responsibility for a patient's care. One community hospice nurse reported that in her geographical area of responsibility the district nurses were "really hot on with that now" (Focus Group 1:125), but there was also concern that the use of the plan was patchy, possibly due to the novelty of the document. "not everybody is aware of these things" (Focus Group 1:132). The key to assessing the impact of relevant and potentially useful documentation therefore, will always be moderated by the extent to which it is taken up.

Although several patients reported showing their Supportive Care Plan to their families, the carers in this study had not seen any documentation providing opportunities for the patient to record their PPD. One carer said he would value information regarding the procedure

around end of life care, saying he would find it helpful to have the process mapped out in some detail:

*You tend to think you get the broad picture sorted out and rather assume the details will take care of themselves, but they don't necessarily you know. (Carer 1:337-339).*

### **Patient Ability to Discuss their PPD.**

Another important factor intricately related to the effectiveness of tools and skills to 'Enable the Patient Voice to be Heard' is the patient's ability to discuss their PPD. Understandably, some patients found this a very difficult subject to talk about, and some were not open to discussion. When asked if they talk much about death and dying at the hospice a patient gave the following reply:

*(speaking quite gruffly) I never bring it up duck. I try and pass on that cos when it comes it shall come but I never want to look at that path. Are you with me? (Patient 2: 128-129)*

A hospice community nurse gave an example of a patient, who although he had agreed to receive palliative care from the hospice, simply refused to talk about the possibility of his future death.



*... a gentleman I've been to see this morning er.... he wants to be resuscitated but wants to be at home... so there is often conflict... views of a difficulty perceiving how the future might be with disease progression... I think I talked about well when you're not as well and he said "Well I hope not to deteriorate any further.. I hope to stay as I am now."*  
(Focus Group 2:107 &114-118).

A carer reported a similar situation with her husband who simply refused to discuss either the possibility of any deterioration of his condition or the inevitability of his death:

*So it's difficult to try to talk about 'What do you want to happen when you know you get to the stage where you know that death, death is inevitable?' No. We can't , we can't because I can't get (husband's name) to talk about it. (Carer 2:139-140 & 143).*

Another carer reflected on how he had thought that he and his partner had discussed end of life matters with some thoroughness as they had made detailed funeral and financial arrangements. So confident was this carer about these plans that he envisaged things " 'going like clockwork'. However, when asked about PPD he realised that they had omitted to discuss the question of place:

*We've certainly talked about it quite a bit ... apart from the bit (laughing gently) about where she'd actually .... 'snuff it'. (Carer 1:181 – 184).*

In this case, it is difficult to know if this avoidance of discussion about PPD was due

a lack of desire or ability to discuss this topic or a lack of awareness of the possibility or desirability of such a discussion.

Other patients were open to discussing end of life issues, including PPD. Both in-patient and community staff reported instances of patients who were ready and able to talk, some of whom had already done some thinking around this and were clear about their preferences, including their PPD and were comfortable in having their wishes recorded. Several patients told me that this was not a difficult subject and that discussing their own end of life in such detail "did not bother" them.

It would seem, then, that the extent to which the patient was ready, willing or able to discuss their PPD had a substantial influence on whether their views on their PPD were heard. However, even in refusing to engage in such discussions, the patient voice was heard, albeit in the negative. For example, if the response to the question "Do you want to discuss your PPD?" was a resounding "NO", the patient voice was heard loud and clear.

## **7.5.2 Influences on Opportunity to Speak**

### **Patient's State of Health**

Having the opportunity to speak about PPD impacted on whether or not the patient voice was heard. A patient's state of health could be a major determining factor, for example if a patient became very ill before articulating their thoughts on PPD, a decision regarding PPD was made by hospice doctors in conjunction with the next of kin. In such a case, for some reason the patient had had no opportunity to voice their view, although it may be argued that in some cases the next of kin was cognisant of the patient's opinion and therefore able to speak on their behalf. Although no cases were reported in this study, in theory not all

next of kin would know their patient's PPD. In such a case, the patient's voice would not have been heard because they had not availed themselves of the opportunity to speak about their PPD and a decision would be made on their behalf and in their best interests.

Some staff felt that patients were best placed to speak about this sensitive subject when they were relatively well and not just in terms of physical symptoms. Reporting on a group discussion with patients about PPD, one nurse reported that

*.. what we found and what they found was it's easy to do when they're in a good place... erm... so they're not sort of imminently dying so they can talk about where they want to die, they can talk about it when they're reasonably stable and make those decisions (Focus Group 1:190-193).*

'Being in a good place' was characterised as a time when the illness was stable and symptoms were well controlled and when the patient's psychological state was fairly stable. This would seem to suggest a window of opportunity, a certain moment in time when 'being in a good place' would occur. Some patients echoed this sentiment: one recommended that patients should talk about PPD when they are relatively well and another advocated an early discussion on the topic to alleviate worry and anxiety.

### **The Time Factor**

Another facet of taking the opportunity to speak, which also involved the time factor, was that patient decisions sometimes changed along the illness trajectory. This seemed particularly apparent to hospice staff. One hospice social worker noted the following:

*What somebody chooses to want or what they think is best for them at the beginning of this pathway journey can completely change when it gets towards the end of that journey.. and sometimes you've got to sort of re-visit that. (Focus Group 2:268-271)*

This implies that some patients may need more than one opportunity to speak about their PPD and there could therefore be a need to review the topic on subsequent occasions, in order to ensure the patient's current wishes are expressed.

### **Availability of Someone to Tell**

Another condition under which the opportunity to speak could be actualised concerned the availability of someone to tell. Some patients found it easier to talk about their PPD to a healthcare professional such as a GP, community nurse or a member of the hospice staff because of their professional skills in communicating with dying people. One patient described hospice staff as intuitive and approachable and most importantly available to talk to. Hospice staff felt that in the course of their work with patients, opportunities to have conversations with patients about their PPD often presented themselves quite naturally. One hospice nurse observed that intimacy and trust may have had a role to play in this regard. She refers to the intimacy which is generated between nurse and patient when "doing care" which means helping with personal tasks such as washing and dressing:

*We've always said that if you're doing care with somebody, a patient, that's the best time from a nurse's point of view.... I don't know if it's because a patient does feel vulnerable or because they're in that position with you but they do tend to open up to you, you learn so much from the patient when they're in that situation*  
(Focus Group 2:438-439 & 441-443).

A hospice community nurse reported her intention to try to initialise a conversation around PPD even from the first contact with a new patient:

*... certainly at first visit it's there in my mind straightaway and any opportunity to try to push that conversation a little we will do.* (Focus Group 2:478-480)

Conversely, staff felt that sometimes families impeded or even prevented end of life care discussion, either because they judged that avoiding such conversations was an effective mechanism of protection of their patient, or they simply could not cope with the reality of the discussion.

*And if their husbands or sons or daughters got upset then they stopped because they didn't want to cause any more pain* (Focus Group 1:207).

In direct contrast to this, one carer recounted her disappointment that she had failed to elicit her husband's views around his wishes and preferences regarding end of life care, including PPD. The fact that this carer did not know "what was in his mind" was a cause of some anxiety which encompassed consideration of her own mortality:

*I've talked about I'm afraid of what would happen to (husband's name) if I died. That is my biggest concern..... And so that worries me in case I suddenly had a heart attack or something and died suddenly and what would happen? So I do think about death regarding myself. (Carer 2:89-9- & 95-96).*

### **Finding the Right Moment**

A related condition of having the opportunity to speak may be described as 'finding the right moment'. There was no general agreement as to what constituted such a time: but the experience of both staff and patients suggested that such a time existed for each individual. Staff reported instances of such conversations happening on admission to the inpatient unit or at the first community visit for some patients, whereas other patients declined such opportunities until a later date. An inpatient unit nurse expressed it thus:

*.. it's a sort of a conversation that just happens, it's no set date, you just end up sitting there one day, talking to the patient .... And you end up going down that road and then you.. from that it just snowballs on... But I don't think there's a set time when cos everybody's different.*

(Focus Group 2:420-423 & 426-427).

The concept of 'the right time' to discuss PPD seemed to be more than a belief in the power of spontaneity, but moreover, a desire on behalf of staff to be responsive to patients' needs and desires. Within this patient-led philosophy, staff felt able to prompt potential discussions about PPD by reference to documentation in which to record their preferences, but this was always within the confines of supporting and promoting patient autonomy.

Patients too expressed a range of views as to when this 'right time' might be. Some felt that immediately following diagnosis of a terminal illness would be too soon because news of such import requires time to process. Others took the opportunity to record their wishes and preferences via the Supportive Care Plan as soon as they became aware of its existence. The overarching theme was individuality: even patients who were comfortable with their status as recipients of palliative care felt that it was important to allow the right time to emerge to discuss such details of end of life care as PPD, rather than expecting everyone to conform to some extrinsic notion of the appropriate time. One patient who considered herself as very able to talk about end of life issues without it being problematic for either herself or her family recalled that accessing 'the right time' with regard to discussing PPD had been an issue for her.

*(name of nurse) the community nurse mentioned I think at one time that they do this .. she may have and I can recall saying "Well I don't want to do that yet". But I felt because things have deteriorated so much over the past few months that the time was right – I only did it just before Christmas. Before Christmastime, about October, so I felt that was the right time for me.*  
(Patient 1:346-349).

Another patient had declined offers of formalising her wishes because she was not yet ready to do this and she felt that she would recognise if and when the right moment emerged and wished to retain control over this matter.

*I've always wanted to do it on my terms and it's... the way I am*  
(Patient 4:291).

In these ways, then, finding the right moment could impact on whether patients experienced the opportunity to speak.

The carers in the study felt that the right time to discuss PPD would be earlier rather than later in the illness trajectory. The reasons given for this view were varied. One was in order to ensure enough time to make any necessary practical arrangements. A second reason was so that the patient could be involved in any decision making whilst they were still able to articulate their wishes and preferences: as one carer put it graphically:

*...it's affecting his memory and his concentration and everything else and if and when he gets to the stage where he's all these faculties have gone there's no point in talking about it then. (Carer 2: 278-279).*

A further reason cited by one carer was to give time to come to terms with the reality of their patient's oncoming death. In recommending a conversation regarding PPD to be held as soon as possible after the initial diagnosis of terminal illness, one carer said:

*I would encourage everyone to do it, to get familiar with it. I mean it's got to be faced anyway so you might as well get the idea into your head early on rather than just putting it off. (Carer 1: 233-234).*

For some patients, however, the process of 'finding the right time' would remain irrelevant because they did not want to avail themselves of such an opportunity, usually as an exercise of personal choice. For one patient, a very particular reason was given to account for the absolute impossibility of there ever being a right moment to discuss PPD. This patient



explained that if she decided to end her own life at some point in the future, she would not want to implicate hospice staff as colluding with her by discussing and recording any plan she might make to do this.

*I wouldn't want to discuss it with anyone that could then be in any trouble whatsoever, you know..... to discuss it under these circumstances you have to have a full and frank discussion and I feel that isn't really the right thing to do if ... part of that discussion would be against the law. (Patient 4:366 & 371-374).*

Therefore for a patient considering suicide and not wanting to implicate the hospice, all extant systems and documentation were irrelevant. This was a startling reminder of how UK societal norms around death acted as limiting factors on the processes at work in 'Enabling the Patient Voice to be Heard' regarding PPD.

### **7.5.3 Influences on Permission to Speak**

Linked with having the opportunity to speak was the consideration of whether or not patients required permission to speak. Patients' views about this ranged from those who felt they definitely did not need anyone's permission to those who had not spoken about this because they felt they had not been granted permission.

#### **Not Needing to Gain Permission**

Some patients demonstrated their lack of need to gain permission to speak by firmly declaring their PPD even when this was at odds with professional advice and family wishes. One community nurse cited an example of a patient in need of a high level of nursing care

who said they wished to return home to die, but their family said they could not support them and the nurse informed them of the extremely patchy availability of home nursing care at that time. The patient, in full command of their faculties, responded by saying 'This is my choice, this is my decision'. Other patients felt that they did not need permission to decline such a talk: when asked how she would react if someone asked her if she would like to talk to somebody about her end of life preferences, the patient replied emphatically in the following manner:

*I'd've said NO THANK YOU. I DON'T KNOW WHY YOU'RE ASKING ME.* (Patient 4:250).

### **Gaining Permission From Hospice Staff**

Some patients had considered their choices by themselves but had been unable to vocalise their thoughts until asked by a member of hospice staff. For some, gaining permission to speak in this way came as something of a relief:

*I thought, "Oh I'm glad in a way that they'll they talk about it because really I wanted somebody to talk to about it, but couldn't really.* (Patient 6:104-105).

Patients who expressed relief when they perceived they had been given permission to speak by hospice staff, sometimes cited family reluctance to talk about this matter. Such reluctance was a barrier to speaking because the family found the subject upsetting or because the patient wanted to protect the family. One patient talked about 'shielding' his family from the harsh reality of his impending death.

## Gaining Permission From Families

Some families were able to grant permission to speak by welcoming and supporting the patient's raising of the topic and their decision making. When one patient showed her Supportive Care Plan to her daughter they had a very positive conversation about the details:

*.. she says "That's good" she says cos I don't want you lying on a trolley (referring to local hospital A&E department) night and day in the corridor at the A&E you know," she says "at least at the (name of hospice) you're looked after, you're taken care of erm... you'll just die with dignity" and I said "Exactly, yeah". So you know she's all for it. Yes. (Patient 9:208-210)*

One carer in the study said emphatically that death was not a taboo subject between himself and his partner:

*..it's certainly not a taboo subject, it just crops up periodically and in passing, as it were. (Carer 1:109-110).*

This would seem to suggest that granting permission to speak about PPD would be a non-issue for this couple. However, as they had only discussed issues such as diagnosis, hospital attendance and funeral arrangements, and not PPD, their views on issues around patients gaining permission to speak from their families, were unknown.

Hospice staff saw themselves as granting patients permission to speak in terms of being available to listen, rather than having power to grant permission or deny permission:

*...but I think we are very good at doing that and listening to what the patient wants really. Although we're quite happy to look after them here...it's their choice.. if they want to die at home.. then we know that's a very important decision .. and it's got to be acted upon.. quickly really. (Focus Group 1:101-104).*

### **Interactions with Other Patients**

Interacting with patient peers also had a role to play in having permission to speak. Some patients first learned about the possibility of recording their PPD from conversations with fellow patients:

*... I just sat and I hear him say "have you done your supportive care plan and that?", so I said to him, I says "you know excuse me, what that like, what y'on about ?" so they told me and said "ain't you done one?", I said "no", he says "Well ask either (name of nurse) or (name of nurse) about it and see what they say. (Patient 5:237-240)*

This patient went on to find out more information from nursing staff and completed their paperwork that same afternoon, thus illustrating the process of gaining permission to speak through the acquisition of knowledge mediated by a well informed and encouraging patient colleague. Another patient reported that learning about the Supportive Care Plan at the Patients' Forum (patient user group at the hospice) prompted their thinking on the subject and helped frame a subsequent conversation on the matter with their family. Gaining permission to speak about PPD from conversations with fellow patients was part of a larger picture of being able to speak about death in general amongst the hospice patient community. Some patients found that people in similar circumstances to themselves were

better able to empathise, even than close, loving family members. There seemed to be shared understandings regarding the meaning of living with a terminal diagnosis which was not accessible to those outside this community. One patient said that although family members say " I understand" they cannot understand because they are not experiencing the illness first hand. It is as if the shared experience of the patients created permission to talk freely about issues that may have been difficult to discuss in quite the same way with others outside this circle. For example, one patient described a very frank discussion about coffins which took part in the patients' lounge one afternoon:

*And we were laughing cos someone walked past and said "There's a right good atmosphere in here, see you laughing about and we said "Yes we're talking about coffins (laughing heartily). Now you wouldn't do that at home!" (Patient 7:270-273).*

Several patients expressed views regarding UK society's attitude towards talking about death. There was a general perception that talking about death was taboo or 'the big no no'. Some found this burdensome: they contrasted their time at the hospice where they could speak freely about death and dying with their time in society in general when they felt they had to consider other people's adverse reactions before deciding what to say. Moreover, sometimes the hospice patients felt oppressed by people's inability to accept their need to talk about their experience of terminal illness. One of the patients who thought that UK society in general does not talk about death made the following observation:

*I think they just sort of ...oohh....put a block on it, I think they're just sort of in denial sort of thing.. they don't want to think about it.. erm... so I think .. I think in that case it makes it harder for you [meaning the dying person] come the time and harder for the family. (Patient 9:334-336).*

Having permission to speak about PPD and death and dying in general within the hospice community suggests that part of the process at work here concerns the hospice becoming a place where such matters could be discussed:

*But I just think it's easier to talk ... plus everybody here isn't involved in your family life.. you can take two steps back sort of thing... even though we're all in the same boat they don't know your family. (Patient 7:112-114).*

Patients, then, can find permission to speak within this space if they wish and equally they are free to decline such an opportunity.

#### **7.5.4 Influences on Support**

An allied yet distinct component of 'Enabling the Patient Voice to be Heard' concerned the level of support available to patients. How much support was experienced or desired by individuals varied from those who required none or little because they found the process of engaging with PPD easy to those who perceived that having staff available to talk to strengthened their resolve to explore their PPD.

## **Hospice Staff Willingness to Listen**

Several patients cited instances of hospice staff listening to their views on PPD as being supportive. The sheer availability of staff within the hospice setting was felt to be most helpful in this regard

*It's knowing that like (name of hospice community nurse) has been this morning, but I know that if I wanted to ring and talk to her again, I could ring her now and she'd come back.... Or like I say I could ring (name of hospice) and ring them any time.*  
(Patient 5:396-7 &400).

## **Perception of Hospice Staff as Possessing Necessary Skills**

For some patients it was not just that hospice staff were willing to listen to their views, it was the perception amongst patients that staff possessed the necessary skills to facilitate such a sensitive conversation.

*...the staff I think are very intuitive.. erm (pause). They make a point of coming and talking to us you know and just having a sit down chat and I'm sure from that you know there's an awful lot of reading between the lines going on (Patient 4:337-340)*  
*...So I'm sure if they felt that erm that maybe it's worth a prompt [meaning PPD conversation], they would give one. (Patient 4:342).*

When asked if they would like to talk about PPD with another healthcare professional involved in their care, such as a GP or district nurse, one patient clearly considered the hospice staff as the better option:

*The young doctor who's there explained everything as well you know and I prefer to talk to them because you know I wouldn't want to talk to anybody else either.*

(Patient 2:176-177).

One patient described how her relationship with a particular hospice nurse had built up over time and how she tended to seek out this nurse to discuss her problems because this nurse had been with her from the beginning of her time at the hospice.

*And I wouldn't dream of not asking any of the other nurses because they're all so lovely but if (nurse's name) is there, which she is most times... So I say "Well (name) can I have a minute when you've got a minute?" ... So you do tend to gravitate towards one particular nurse and I think that's quite natural, it's nature.*

(Patient 1:274,277-279).

This patient recalled how this nurse had originally broached the subject of recording the PPD quite early on along the illness trajectory but the patient firmly declined this offer at that time. Later on, as the patient's condition deteriorated, she decided to ask this same nurse to help her record her wishes on a *Supportive Care Plan Document*.

Hospice staff also saw listening to patients' views as a vital component in supporting the patient voice. 'Listening to what the patient really wants' (Focus Group 1:101) was seen as the starting point for any staff action or intervention which might be necessary to realise the patient's PPD:



*If a patient said... "I don't want to die here, I want to be at home" then I think we'd pull all the stops out to get that patient home.....it's their choice (pause)*  
(Focus Group 1:96-98 ).

Whilst this approach undoubtedly supports the patient's voice, it is a reactive approach which relies on the patient taking the initiative and expressing their view in the first place.

However, agreeing with the patient voice in this manner and taking action to ensure the wishes are achieved may be seen as an act of solidarity with the patient voice, an act of supportively 'standing with'. A day hospice nurse cited a more pro-active approach to supporting the patient voice that she had experienced via the hospice user group The Patients' Forum. At this meeting of patients and staff, staff had taken the initiative and asked the patients whether they would welcome the opportunity to talk about their PPD at some time. The patients present at this occasion expressed their willingness to speak about this issue and their particular desire to talk to staff about this. One day hospice nurse recalled the encounter in the following manner:

*Well, we , we actually asked the patients didn't we? Erm how they felt about this collectively. The patients wanted to talk about it and wanted to talk openly about it with staff* (Focus Group1:187-189).

Therefore, actively creating opportunities for patients to express their PPD, by asking them direct questions about this may be an important avenue of support for some patients.

## Documentation

Support for the patient voice being heard was evident in the existence of documentation in which the patient's PPD could be recorded. Documentation may act as supportive in two different ways. Firstly, it may serve to prompt members of staff to attempt to elicit information from patients. In particular the hospice staff viewed the Supportive Care Plan document, as an effective means of discovering the patient's PPD.

The Supportive Care Plan was described by hospice staff as "a very valuable document in patient choice" (Focus Group 2:263), particularly because this document is shared across the care team with the patient retaining a copy, with copies being sent to the patient's GP and other relevant healthcare professionals. It was felt that such a mechanism for the communication of information could influence the potential achievement of the patient's PPD in a positive way. Staff noted that because this document could be initiated by any member of the care team, the responsibility for ensuring its completion could be unclear. Whilst this supported patient choice as the patient could select a favoured staff member with which to share such sensitive information, there was a danger that the form would never be initiated:

*Who should say who it should be? I mean I guess you've got to say it's got to be somebody otherwise it might get passed to everybody, but who actually does it? (Focus Group 2:542-544).*

Some patients felt more confident about achieving their PPD by having their wishes recorded in the Supportive Care Plan and by the knowledge that the whole care team had copies. It also served to bring about a certain peace of mind, particularly when thinking about the

levels of stress to which the family would be exposed as death approached for their loved one. One patient expressed this thought thus:

*...when someone gets to that stage, sometimes the family are so full of grief they can't remember what you've said you wanted (pause) . They forget or they're in a panic or whatever, so if it's all written down then they can make sure that that's what I wanted. (Patient 1:206-210).*

One carer expressed a similar sentiment around supporting the patient voice by having access to their documented wishes as this could assist in "avoiding anxiety and confusion towards the end" (C1:164). He also felt that this could have the additional positive effect of bringing a sense of peace of mind for all, including to those who are left:

*Yes, it'd be better if you get everything organised so you know what's happening, everyone knows what's happening and then .... if things run smoothly then I think it's less traumatic for those involved. (Carer 1:171-173).*

On the other hand a potentially unsupportive aspect of the *Supportive Care Plan* is that it does not explicitly use the word death. In the section headed "Future Plan and Place of Care", the question is asked "What discussions have taken place around where the patient would like to be cared for now or in the future?" It may be argued that staff would use this section to explicitly refer to preferred place of **death**, and patients in the study certainly did record their PPD using this document. However, the fact that the actual phrase Preferred Place of Death does not appear on the form, may be a weakness or a missed opportunity to help the patient speak about their PPD and so the level of support here may be questioned.

Routine hospice case notes were another source of documentation which had potential to support the patient voice with regard to PPD. Staff were aware that this could be recorded in the notes at any time from the very first meeting with a patient right through to the last day of life, as the subject arose in the course of therapeutic conversations with hospice staff. The audit of casenotes which was conducted in Phase One of this study showed that a small number of patients recorded their PPD by this method.

Whilst case note entries may be a valid potential avenue of support, within the notes there is a facility to record *patient not open to discussion*. In terms of supporting the patient voice, this may be viewed in two ways: firstly, the lack of a specific requirement to ascertain the patient's PPD to record in the case notes does not actively encourage disclosure of PPD. Conversely, it may be argued that recognising that some patients might not be open to discussing this issue recognises and supports patient autonomy on this highly sensitive question about their own imminent death. During a focus group, one member of staff posed the following question:

*What if they're never open to that discussion? If they're so defended that they can't go there. Who makes that decision then?* (Focus Group 2:522-523)

Another member of staff replied as follows:

*They've made it I think haven't they? And I think they'll probably end up in the hospital.* (Focus Group 2: 527)

At a more philosophical level, documents which record the patient's PPD provide an official receptacle for the patient's view. The sociological concept of legitimation may come into play here. Legitimation may be defined as 'Being in accordance with established or accepted patterns and standards' (Little Oxford English Dictionary, 1976). The sociologist Peter Berger (1991) argues that legitimation is the process by which validity is ascribed to a certain action and that by this process normative dignity is given to practical imperatives. With regard to documentation which receives and records the patient voice, the very existence of such a document gives legitimate status to the action of expressing and recording one's PPD. It suggests to the patients that recording one's PPD is 'the done thing' and may enable some to respond to the notion positively and thereby enable those who want to, to access this opportunity more easily. It may be argued that knowledge about such a document's existence within the hospice patient community could increase the levels of uptake.

One patient's experience of interaction with the Supportive Care Plan depicts a positive and 'matter of fact' acceptance of the notion of recording one's PPD which may reflect the process of legitimation:

*I heard about it at the Patients' Forum and so I asked about er doing it there and then eventually I did do it with one of the nurses cos (name of nurse) or (name of other nurse) do it with you, so I did it with one of them ..... (Name of nurse) gave me... cos it's a very easy form to fill in. (following said with positive emphasis) **yeah it was alright!** (Patient 7: 128, 130-131, 133 & 138).*

If legitimization of recording PPD is supportive of the patient voice in terms of framing this as acceptable and established, wider societal trends and taboos may also play a role in the level of support afforded. Providing more choice for patients has become something of a priority in UK healthcare in recent years with a raft of documents designed to enable and support the rights and choices of individuals. (e.g. Health and Social Care Act, 2012; NHS Choice Framework 2012/13). This includes choosing one's place of care for death.

### **The Positive Perception of the Notion of Choice**

In UK society, people generally enjoy high levels of choice in areas as diverse as education, employment, housing, food, size of family, clothing and leisure pursuits. Individuals enjoy independence and freedom from external control in many spheres of their day to day living: this is so much the norm that it is often taken for granted in the 21<sup>st</sup> century UK. Western democracies highly prize such autonomy, with its implication that choice is morally correct because each person is a sentient being and thus innately in possession of a life which is their own to dispose of as they see fit, free from external coercion. The perceived wisdom is that each individual knows best what they want, need and desire. This notion which seems to be woven into the tapestry of UK society was demonstrated in the staff focus groups with regard to enabling patients to achieve their PPD. As one in-patient unit nurse said:

*And I think it's important for people to feel like ... they have got a choice. They've got choices everywhere else in their lives, ... why shouldn't they choose about ... how their death is gonna be and about where it's gonna be and who's gonna be with them (Focus Group 1:172-175).*

A hospice social worker spoke with conviction about the importance of choice:

*...enabling people to have choice is part of your values and ethics of your own profession so it's ingrained within you.....it's the framework in which your own profession works in. So I'd be failing in my duty if I didn't at the start with what is the person's choice, what do they want? (Focus Group 2:224-229)*

These observations seem to be very much in keeping with the trend in UK society supporting individual autonomy and choice. The first comment comparing the number of choices available to people in other areas of their life compared with end of life choices, highlights the fact that terminal illness restricts the range of choices available to people. Due to symptoms and management of their illness, individual's activities in life may be severely limited. If supporting the patient choice is seen as a priority, as in the case of the passionate social worker in the study, it may be argued that opening the opportunities of choice around end of life decisions assumes an even greater significance for supporting the patient voice than is perhaps evident at first glance.

This view is tempered by the reality of how people's end of life care choices are followed through: whether in reality it is possible for everyone to achieve their PPD. Staff characterised some patient's wishes as unrealistic due to the lack of availability of services. One hospice doctor encapsulated this kind of thinking as:

*I think sometimes we, we present PPD as a sort of menu of choices and actually in reality it probably never is... just thinking about this single elderly gentleman who said 'I want to die at home'. You know you can write that down but the reality is he is not going to die at home in in all probability almost 99%. (Focus Group 2: 696-701).*

Hence, service provision, or lack of service provision comprises a limiting factor on societal ideas around personal autonomy.

There may be a certain lack of awareness about choices actually available to people around end of life. Several patients in this study said they had not considered the potential availability of different settings for their death, such as home, the hospice, nursing home or hospital, let alone choosing which one might be appropriate for themselves. One patient expressed it thus:

*I don't think enough people realise that they have got choices... or where to die... I think it's important that it's talked about and sorted out.*

(Patient 7:253-254).

This may be seen in two different ways. On the one hand the fact that patients are unaware, to a lesser or greater degree, of choices available to them regarding PPD seems to suggest a grass roots scenario at odds with the UK government's vision of enabling more patient choice. On the other hand the fact that this subject is starting to be broached with hospice patients is in keeping with this current trend. It may be argued that this provides a measure of support for the patient voice being heard.

### **Death as Taboo**

Another societal trend which is of direct relevance to supporting the patient voice regarding PPD is the perception that death is a taboo subject. Some commentators have noted that in some ways UK society is obsessed with death as the media seems to be saturated with reports of violent, sudden and unexpected deaths (Seymour, Almack and Kennedy, 2010).



However, the reality of 'ordinary' death and dying is rarely discussed either in the media or in society in general. The End of Life Care Strategy (DH, 2008) names death as society's last great taboo and finds evidence that most people find it hard to engage in advance with the way they would like to be cared for at the end of their lives. A 2012 survey of British Social Attitudes (National Centre for Social Research) reported that 69% of the UK public had not talked about end of life care issues, even though many cited such advanced planning as a positive opportunity to consider values and goals for care and to prepare for death.

Patients in this study were aware of attitudes in the community at large regarding talking about death and dying. When praising the opportunity to talk about death within the hospice one patient contrasted her experiences in the community with her experiences in the hospice:

*It's a good thing really, because I mean a lot of people'd cry and be upset, and say "oh you can't talk about things like that" but we (meaning patients and staff) laugh and joke about it. (Patient 5: 118-119)*

When asked about why people in general don't want to talk about death and dying, one patient reflected the following:

*They're frightened aren't they?... It's something, it's the big 'no no' what you don't talk about isn't it really (Patient 7: 261 & 263).*

It may be argued that this lack of openness about talking about death and dying makes supporting the patient voice in expressing their PPD a difficult task. It is counter-cultural and

therefore will be unable to access wider support from influential societal agencies such as the media, educational institutions and the arts. There are however, developments in society to promote change in attitudes about death and dying such as the government's EOLC Strategy (DH, 2008) and the National Dying Matters Coalition (2011), which exists to change behaviour and attitudes which engender negative consequences of not talking about death. In addition the hospice movement and those professionals across the healthcare economy involved in the delivery of palliative care are raising awareness of these issues with those who are affected directly: terminally ill people.

'Enabling The Patient Voice to be Heard' by allowing interaction with the subject of PPD, then may be seen as both supportive of this movement for social change and also supported by it.

## **7.6 Summary**

In this chapter describing the core category it has been demonstrated that ascertaining and recording the patient's PPD acts as a means of enabling patients to have their views heard on this topic. The degree to which patient voices are heard is influenced by the level of tools and skills mastered, by the extent that opportunities to speak arise, by the degree to which permission to speak is granted or required and by the level of support available.

Chapter Eight will present the Literature Review

## **Chapter Eight      Integration of the Literature with the Emerging Grounded Theory**

### **8.1 Introduction**

Building on the initial literature review presented in Chapter Three, this chapter presents the substantive literature review which was undertaken after the analysis of the focus groups and patient and carer interviews. The search strategy is explained, and the literature is critically reviewed.

### **8.2 Literature Review Search Strategy**

#### **8.2.1 The Search Terms**

In accordance with the constructivist grounded theory approach adopted in this research, the search terms for the review arose out of the research study. Therefore, the hospice context and the notion of the patient voice on PPD guided the formulation of the search terms. With these parameters in mind, two search questions were formulated:

- What research has been done on the hospice patient voice on the topic of PPD?
- What research has been done on phenomena (mechanisms or attitudes) which enable or disable the hospice patient voice on PPD?

Building on these search questions, a set of search terms which could be used in electronic database searching was developed. The search terms were: hospice patients, terminally ill patients, voices, views, preferred place of death and end of life wishes. Inclusion and exclusion criteria were then specified to focus the search in as clear a manner as possible in order to find literature which addressed the search questions, and provide a measure for discarding literature which was irrelevant. These were peer reviewed articles; abstract

available; all adult; 2006-2014 and qualitative studies. The timeframe of 2006 – 2104 was significant as it would chart the impact of the UK government's End of Life Care Strategy (2008) which specifically recommends that terminally ill patients should express and record their preferences with regard to the end of their lives, including the preferred location for their death.

Qualitative studies was selected as an appropriate inclusion/exclusion criterion because such studies were judged to be most compatible with the research design of this study which is largely qualitative. Qualitative studies are concerned with exploring meaning and phenomena in their natural setting. Their results are descriptive and interpretive in contrast to quantitative studies which employ hypothesis-testing methodology to produce results which are numerical and statistical. (Aveyard, 2010). Initially, then, the latter were judged to be less relevant to the search questions of this literature review.

However, it is accepted that some quantitative studies do address people's views, and therefore excluding them at the outset of a search could potentially lead to the omission of important work. A pragmatic approach was taken towards this dilemma. In the initial database search, qualitative studies only were searched for. However, it was known that two planned subsequent data base searches (AMED and CINAHL) would automatically include quantitative papers, due to the non-availability of a qualitative limiter. This would provide an opportunity to pick up any relevant quantitative work.

### **8.2.2 Searching via Databases**

Initially a combined search of all electronic health databases on EBSCO was conducted using combinations of the search terms hospice patients, OR terminally ill patients, AND voices,

AND views, AND preferred place of death AND end of life wishes. Inclusion/exclusion criteria of peer reviewed articles; abstract available; all adult; qualitative studies and 2006-2014, were deployed via the database limiters. This search produced 85 possible papers, but on a screening of these abstracts, only three papers were eligible for reviewing. 82 papers were rejected because they did not address the search questions but covered topics such the hospice experience in general, treatments and symptoms, assisted suicide and service provision.

The four health data bases of AMED, CINAHL, MEDLINE AND PsychINFO were then searched separately to ensure a thorough searching for relevant papers. The same search terms as above were used, but the individual databases each had different limiters available. For AMED the following limiters were employed: abstract available and 2006-2014. For CINAHL the limiters were: 2006-2014; peer reviewed; abstract available; excluding MEDLINE and all adult. The MEDLINE limiters were 2006-2014; abstract available; all adult and qualitative highly sensitive. The PsychINFO limiters were 2006-2014; abstract available; peer reviewed; adulthood and qualitative study. This yielded a total of 808 papers potentially eligible for review.

### **8.2.3 Screening and Appraising the Papers**

The 808 papers were then screened in the following way. Each title and abstract was considered with reference to the search questions of this study. If a paper was deemed relevant to the questions, it was retained, if not it was discarded. Therefore, it was asked of each title and abstract: Is this paper relevant in some way to the hospice patient voice on PPD or does it discuss a phenomena which enables or disables the patient voice on PPD? This yielded a total of 21 papers eligible for review.

Two papers from 2005 were included in this selection (Clayton, Butow and Tattersall, 2005 and Pevey, 2005). Although they fell just outside the timeframe of this review, they were included due to frequency of citation and because they addressed the patient view directly and therefore contributed important insights into this discussion. When these 21 papers were added to the three papers from the combined database search, a total of 24 papers was reached.

The 24 papers were then retrieved and full text screened. The purpose of the full text screening was to assess the quality of each paper in order to judge whether or not it should be included in this review. A structural process was applied to each paper in order to examine them in terms of rigour and relevance to this study. As this review includes both qualitative and quantitative studies, different appraisal tools were utilised as appropriate.

For qualitative papers a modified version of the appraisal tool for qualitative studies designed by the *Critical Skills Appraisal Programme (CASP)*, (Better Value Healthcare, 2013) was employed. The appraisal considerations included whether there was a clear statement of the aim of the research and whether a qualitative methodology was appropriate; whether the research design, recruitment strategy and data collection methods were able to address the aims of the research; whether the relationship between researcher and participants and ethical issues had been adequately considered; whether the data analysis was sufficiently rigorous, including the provision of a clear statement of findings and finally the value of the research was considered.

For Randomised Control Trial studies a modified version of the CASP tool for

RCTs (Better Value Healthcare, 2013) was employed. The appraisal questions included whether the trial addressed a clearly focused issue; whether the assignment of patients to treatments was randomised and if all of the patients who entered the trial were properly accounted for at its conclusion; whether patients, health workers and study personnel 'blind' to treatment; whether the groups were similar at the start of the trial and were treated equally apart from the experimental intervention; the size of the treatment effect was considered as was its precision; whether all clinically important outcomes were considered; whether the benefits were worth any harm and whether the results be could be applied in the context of this study?

For Cohort studies, a modified version of the CASP tool for cohort studies (Better Value Healthcare, 2013) was employed. The appraisal questions included whether the study address a clearly focused issue; whether he cohort was recruited in an acceptable way and that exposure was accurately measured to minimise bias; that confounding factors had been identified and whether the follow up of subjects complete enough; that the results were given and considered in terms of their precision, believability, comparability with other evidence and applicability to other contexts and any implications for practise were presented.

For surveys, a modified version of an appraisal tool developed by Crombie (2007) was used. The appraisal questions included whether the study addressed a clearly focused question with an appropriate research design for the question; whether the method of selection of the subjects was clearly described an avoided bias in sample selection; whether the sample was representative with regard to the population to which the findings will be referred and whether a statistical power calculation was necessary and reported; whether a satisfactory response rate was achieved; whether the measurements were likely to be valid and reliable;

whether the statistical significance was assessed, confidence intervals given for the main results and confounding factor accounted for and whether the results could be applied to the organisation within this study.

Of the 24 papers screened in the above way, eight were excluded at this stage on grounds of irrelevance. Three papers concerned symptom management and care planning; two discussed issues around decision-making regarding life extending therapy; one focussed on the psychological needs of bereaved carers; one reported on the timing of physician referrals to a hospice and one describe carers' information needs on the physical aspects of death. One further paper which had been handsearched from a reference list of one paper was added, meaning that 17 papers were included in this literature review.

Figure 8.1 illustrates this process.

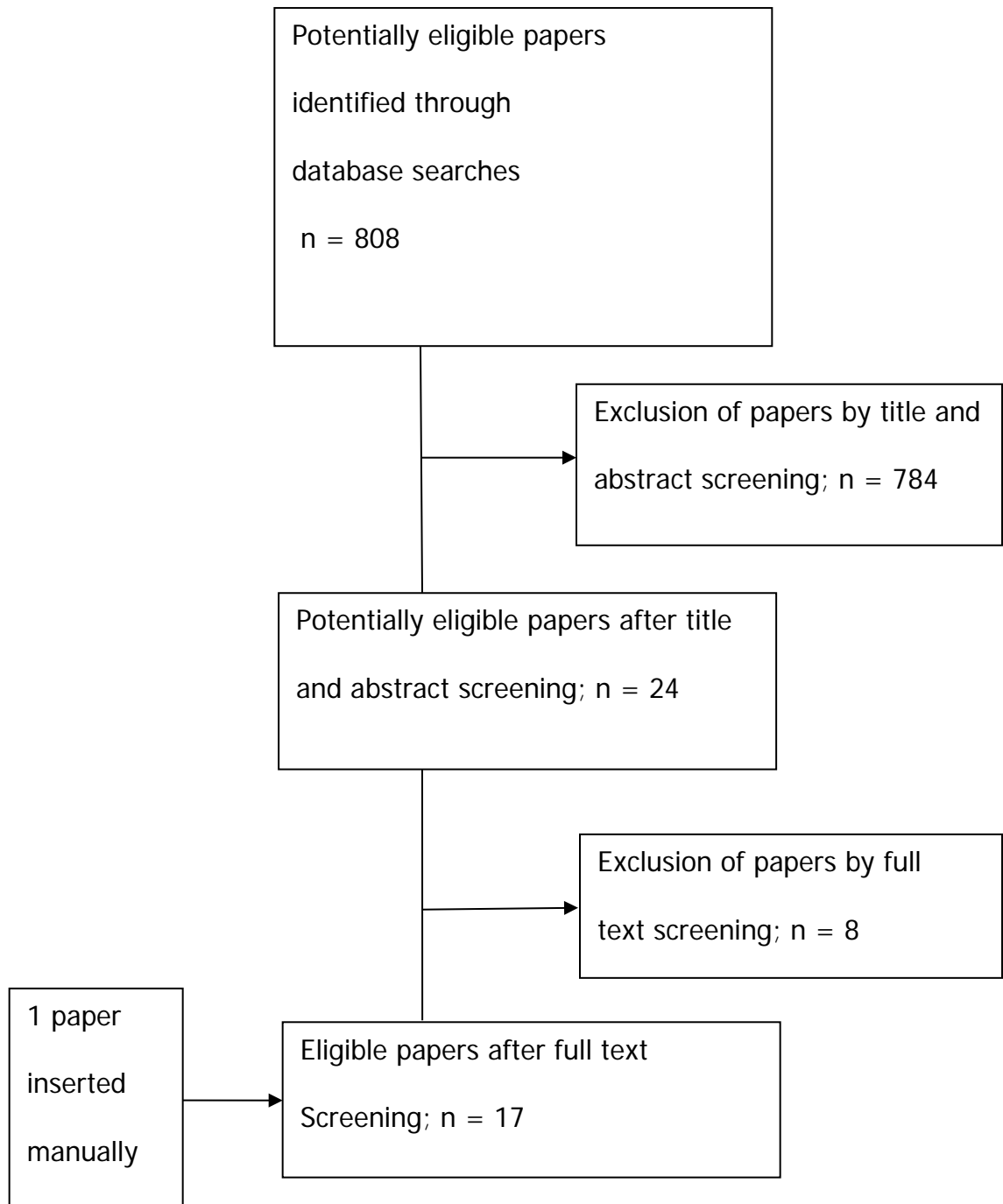
#### **8.2.4 The 17 Papers in the Review**

Much of the research was of UK origin (11 papers: Murtagh and Thorns, 2006; Shah et al, 2006; Barnes et al., 2007; Barclay and Maher, 2008; Holdsworth and King, 2009; Munday, Petrova and Dale, 2009; Thompson-Hill, 2009; Jones et al., 2010; Department of Health, 2012; Field, Finucane and Oxenham, 2013; Holdsworth and King, 2011). Three papers came from Australia (Clayton, Butow and Tattersall, 2005; Terry et al., 2006 and Aoun and Skett, 2013); two were from the USA ( Pevey,2005 and Van Leuven, 2011) and one came from The Netherlands (Luijkx and Schols, 2011). End of life care in these developed westernised countries has similar characteristics to those exhibited in UK palliative care and therefore inferences made can easily be transposed across the individual national contexts. The process employed for the selection of papers was checked by one supervisor, thus ensuring that a rigorous search strategy had been upheld. The search



strategy is depicted in Figure 8.1 Literature Review Flow Chart and the appraisal of the papers is reported in tabular form in Figure 8.2 Summary of the Literature.

**Figure 8.1 Literature Review Flow Chart**



### **8.3 Reviewing the Literature**

Amongst GT practitioners, there has been debate about how to best use existing literature in a research study (El Hussein et al., 2014). The purpose of this literature review was to critically engage with the research in the area which my emerging GT addressed (Charmaz, 2014), that is, hospice patients talking about PPD. In keeping with a constructivist approach to GT, the data from my research study retained priority over the literature review (Charmaz, 1990,). In this way, whilst critically engaging with the literature (Thornberg, 2012), I maintained a deliberate commitment to prioritise study data over any other input (Ramalho et al., 2015). Hence, reviewing the literature in critical dialogue with the emerging theory afforded the opportunity to position my research within the literature (Bryant and Charmaz, 2007) and thus articulate the ways in which it added to the corpus of knowledge on this topic.

I approached the task with the following intent: to explore the extent to which the theoretical concepts contained within my emerging GT resonated with the literature in this area (Lee, Long and Boore, 2009). Looking for the concepts of my GT within the literature would potentially strengthen, confirm or challenge the emerging theory and move it on. As part of the constant comparative analysis of this study, engagement with the literature in this way, then, assisted in refining and developing the grounded theory and in 'setting the stage' for the final grounded theory (Charmaz, 2006).

## 8.4 Summary of The Literature

**Figure 8.2 Literature Review Table**

Title, Author & Place	Methods	Results	Rigour and Credibility	Relevance
<p>When &amp; How to Initiate Discussion About Prognosis and End-of-Life Issues with Terminally Ill Patients.</p> <p>Clayton, J.M., Butow, P.N. and Tattersall, A.N. 2005. Australia</p>	<p>Qualitative focus groups: n=19 Patients n=24 Carers n=22 Health Care Professionals Thematic analysis</p>	<p>Patients and carer have different needs for information. Patient autonomy is in tension with professional desire to protect patients.</p>	<p>Method relevant to research design. Recruitment and methods reported clearly. Several researchers checked the analysis. The study received ethical approval.</p>	<p>2005 is outside 2006-2014. Included as frequently cited and about prognosis and end of life conversations with patients, carers and staff. . Death as taboo</p>
<p>Patient speaking: Hospice patients discuss their care</p> <p>Pevey,C. 2005. USA</p>	<p>Qualitative in-depth interviews with patients on hospice at home services n=38 Descriptive analysis</p>	<p>Positive view of hospice at home: human contact, open discussion of death and dying, communication with other Health Care Team and symptom control.</p>	<p>Method appropriate and well described. Ethics not reported: confidentiality measures were. Recruitment by nurses could result in bias in selection</p>	<p>PPD was not discussed specifically. Reports on importance of open discussion of dying. Pre 2006, but relevant as patient perspectives.</p>
<p>Evaluation &amp;ethical review of a tool to explore patient preferences for information and involvement in decision-making.</p> <p>Murtagh, F.E.M. and Thorns, A. 2006. UK</p>	<p>Before and After design (n = 61 before) ( n = 46 after). Statistical analysis using Chi Squared and Mann-Whitney U Test employed.</p>	<p>81.3%, satisfied with information received. 2.7% preferred not to know future details. 1.3% patient made an advance directive. 16.0% statements about their future preferences.</p>	<p>Method well-described; Sample size calculation given. Ethical approval reported. Prescribed questions not allow for in-depth portrayal of patient experience.</p>	<p>Patient autonomy in relation to risk of distress. Ethical need for "opt out". Asking about PPD does not increase distress and improves patient satisfaction and doctor confidence.</p>

Title, Author & Place	Methods	Results	Rigour and Credibility	Relevance
<p>Estimating needs in life-threatening illness: a feasibility study to assess the views of patients &amp; doctors.</p> <p>Shah, S. Blanchard, M. Tookman, A, Jones, L.and King, M. 2006. UK.</p>	<p>Vignettes on perceptions of the seriousness of illness and care needs. Comparative statistical analysis using <i>SPSS</i>. 40 patients (n = 40) 35 physician reports (n=35)</p>	<p>Patients willing to estimate their life expectancy and needs for supportive care. No objection to questions about end of life care. Drs more pessimistic estimates than the patients themselves</p>	<p>Method appropriate and described in detail. Ethical approval and recruitment described. Small sample with low power, but as this is exploratory work has merit.</p>	<p>Not on PPD directly but confirms patients with end stage illness do not object to questions about end of life.</p>
<p>Experience of dying: concerns of dying patients and of carers</p> <p>Terry,W., Olson,L.G., Wilss, L. and Boulton-Lewis, G. 2006 Australia</p>	<p>Qualitative, semi-structured interviews with dying hospice in-patients (n=36) Focus Groups carers of Deceased patients (n=18)</p>	<p>Patients privacy and autonomy very important. Carers felt lack of information about patient's illness and recognition of the carer role;</p>	<p>Methods appropriate; ethical approval reported. Recruitment adequate. Participant &amp; inter researcher checks added rigour</p>	<p>Patients want to control decisions about themselves &amp; keep distinct from family in contrast to prevailing view. Dearth of research amongst this population.</p>
<p>Acceptability of an advance care planning interview schedule: a focus group study.</p> <p>Barnes, K., Jones, L. Tookman, A.and King, M. 2007 UK.</p>	<p>Focus groups 18 hospice patients; 4 relatives. (n = 22). Thematic analysis</p>	<p>ACP in clinical setting viewed positively. Timing: not at diagnosis and should be offered more than once. Healthcare professional (nurse not consultant) should broach this subject.</p>	<p>Method appropriate and well described. Ethics not mentioned: consent described. 2 moderators 20% of coding checked by co-moderator, adds rigour.</p>	<p>Patients and carer voices here. Open to talking about PPD. Want HCP to broach. To be compared with my findings.</p>

Title, Author & Place	Methods	Results	Rigour and Credibility	Relevance
<p>Having the difficult conversations about the end of life.</p> <p>Barclay, S. and Maher, J., 2010. UK</p>	<p>Article to stimulate discussion on what makes end of life discussions difficult for clinicians and patients</p>	<p>Doctors' reluctant to initiate end of life conversations and wait for patients to initiate. GPs hope specialist hospital teams will deal with this and vice versa</p>	<p>Authors are GP and Consultant oncologist, who are thus amply qualified to comment on this issue.</p>	<p>Doctors difficulties with end of life conversations present a barrier to the patient voice. Part of providing optimal care is timely, sensitive, patient-led conversations.</p>
<p>Developing a Patient Preference Questionnaire for Place of Care When Dying Phase 1 – Hospices</p> <p>Holdsworth, L. and King, A., 2009. UK.</p>	<p>Focus groups with patients, carers, bereaved carers and staff (n = 21) with data analysed via thematic analysis. Development of a questionnaire tool with tick box and free text</p>	<p>90% staff claimed to record PPD; most patients and carers said this not happened. PPD should not be discussed during major life event, A consistent and stepped approach favoured Patients should opt out rather than opt in. Language about death should be clear "place of "death" was changed to "place of dying".</p>	<p>Methods were appropriate to the question. Ethical approval reported. Literature search described in detail. Recruitment well described. Focus Groups' two facilitators and group to group checking aided rigour.</p> <p>The questionnaire was included in this paper.</p>	<p>Patient and carer voices in addition to staff. Contrast to some tools developed without user perspective. Patients are open to discussing PPD. Staff practice can be subjective and inconsistent. Can cause misleading recordings of PPD. Can be addressed through training&amp; adoption of consistent approach.</p>
<p>Exploring preferences for place of death with terminally ill patients: qualitative study of experiences of general practitioners and community nurses in England.</p> <p>Munday, D., Petrova, M. and Dale, J 2009. UK .</p>	<p>Semi-structured interviews of 17 GPs and 19 community nurses to discuss experiences of eliciting PPD (n=36).</p> <p>Thematic analysis was used to process the data.</p>	<p>Patients' preferences are dynamic and not fixed. PPD Is identified indirectly and when subject is broached by the patient. GPs reluctant to elicit the PPD Preferences are sometimes co-created with the Healthcare Professional or inferred by staff</p>	<p>Method appropriate to question. Recruitment reported in detail. Rationale for sample size given. Coding explained in detail as was thematic and framework analysis. All researchers collaborated in coding, adding rigour to results</p>	<p>GPs and nurses do not find this easy. Training in communication skills required Danger of indirect approach can disadvantage patients and carers as their voices not heard. Unknown how important this is to patients</p>

Title, Author & Place	Methods	Results	Rigour and Credibility	Relevance
<p>The Supportive Care Plan: a tool to improve communication in end of life care.</p> <p>Thompson-Hill, J., Hookey, C., Salt, E., O'Neill, T., 2009 UK</p>	<p>Description of new tool (SCP) used in acute hospital to encourage recording Of PP of Care (PPC) or palliative patients.</p> <p>Audit of notes (n=45) on impact of SCP.</p> <p>Feedback on tool.</p>	<p>PPC recorded 30% before SCP; 100% post. Future care plan in place 10% before SCP; 30% post. PPC achieved in 71% cases post SCP. Staff reluctant to use SCP. Patients and relatives positive about SCP.</p>	<p>Tool described clearly but not provided. Audit described reasonably. Feedback sample described as "small", but not specified. Audit sample small. Unclear which staff used SCP or if on all types of wards.</p>	<p>SCP now used in the hospice where my study is set. Terminology: PP of CARE avoids use of word "death". Unclear who initiates SCP with patient. Unclear what the triggers for use are.</p>
<p>ACP in advanced cancer: Can it be achieved? Randomized patient preference trial of a care planning discussion.</p> <p>Jones, L., Harrington, J., Barlow C.A., Tookman, A., Drake, R., Barnes K. and King, M., 2011. UK</p>	<p>Quantitative exploratory RCT on effectiveness of an intervention to facilitate planning for end of life n=77</p> <p>Statistical analysis via Stata v.10.0 and descriptive statistics.</p>	<p>89% showed interest or no objection to talking about end of life. Some dissatisfaction with level of communication and care. was. Talking about end of life does not cause undue anxiety &amp; depression.</p>	<p>Recruitment presented. Randomisation described, all participants accounted for. Confounding considered. Blinding not needed. Intervention and outcome measures stated Cronbach's alpha &amp; ANCOVA models.</p>	<p>Not hospice patients but similar patient group. Willing to discuss EOLC Raises staff reluctance to discuss and patient dissatisfaction with communication skills of staff Talking about end of life does not cause anxiety.</p>
<p>Perceptions of terminally ill patients and family members regarding home&amp; hospice as places of care at the end of life.</p> <p>Luijckx,K.J. and Schols, J.M.G.A 2011 Netherlands.</p>	<p>Methods: semi-structured interviews N = 26</p> <p>Descriptive analysis.</p>	<p>For home death, co-habiting partner essential. Support from agencies often needed; Role of family is crucial for home death: if family agree – Yes. If is hospice.</p>	<p>Ethical approval not required Method appropriate &amp; open ended, allowing for voice of participants. Analysis by 2 researchers, adding rigour. Analysis descriptive</p>	<p>Highlights importance of family relationships and dynamics. Actual choice of place of death is negotiated between patient and family. Not patient alone.</p>

Title, Author & Place	Methods	Results	Rigour and Credibility	Relevance
<p>Advance Care Planning in Healthy Older Adults</p> <p>Van Leuven, K. 2011 USA</p>	<p>Qualitative interviews (n=18) adults 75yrs + Secondary analysis of unexpected finding in study on beliefs and lifestyles of healthy older adults</p>	<p>All healthy adults had ACP. In poor health no ACP. Discussing end of life seen as culmination of a good life and not to be feared by healthy but feared by others.</p>	<p>Methods relevant and clear. Recruitment clear. Validity via triangulation. Ethical approval was reported. Unclear if probed regarding why those in poor health not discuss End of Life.</p>	<p>Not in a hospice but informative of wider societal debate on talking about death and social construct of "successful aging" Raises incorporating end of life talks into routine consultations.</p>
<p>Preferences for end of life: views of hospice patients, family carers and community nurse specialists.</p> <p>Holdsworth, L. and King, A., 2011 UK</p>	<p>Focus groups and qualitative interviews with hospice community nurses, patients and carers (n=21).  Thematic analysis</p>	<p>Discussing PPD important to patients, carers. Discussing dying difficult. Carers wished to know patient's PPD. Nurses stated barriers inhibiting PPD talks so did not always engage and PPD not first goal of care planning.</p>	<p>Method relevant to question. Ethical approval reported. Recruitment reported in detail. Patients recruited by participant nurses – could introduce bias; offset by patients being in different focus group from nurse recruiter.</p>	<p>Highlight the potential barriers to the patient voice being heard, that is staff confidence and patient and carer difficulty in discussing end of life.</p>
<p>First national VOICES survey of bereaved people: key findings report DH, 2012. UK study</p>	<p>Postal and online survey including questions on PPD. (n = 49,000)</p>	<p>44% patients expressed PPD; 52% had not; 5% of carers not sure of PPD; 32% of patients knew they were dying; 29% probably knew; 17% did not know; 51% of patients had enough choice about PPD; 23% did not; 26% of carers not sure 82% of patients died in right place; 10% did not and 8% of carers were unsure.</p>	<p>Large sample and validity measures referenced. Confidence intervals and respondent rates were referenced. Ethical issues considered as participants are referred to support if necessary. Fulfils aim of providing systematic information, but quantitative surveys are limited in that there is no "free text" opinion.</p>	<p>CARER not patient views but talking about death and planning for death. Minority doing PPD Majority NOT doing PPD. Significant proportion did not know they were dying – issues around talking. Majority thought patient died in right place? Raises question whether knowing PPD matters. This survey cannot tell why a minority expressed PPD</p>

Title, Author & Place	Methods	Results	Rigour and Credibility	Relevance
<p>A longitudinal study of end-of-life preferences of terminally-ill people who live alone. Aoun, S. and Skett, K., 2013 An Australian quantitative study</p>	<p>Quantitative semi-structured questionnaire on PPCARE &amp; PPD at 2 points on illness trajectory and achievement of PPD (n = 43). SPSS statistical analysis &amp; descriptive stats via Nvivo8.</p>	<p>Preferences for a home/hospice death. Congruence between preferred and actual place of death was between 53% and 41% dependent on whether this was first or second data collection point</p>	<p>Ethical approval, recruitment &amp; methodology clear. Semi structured questionnaire allowed for richer, open-ended data. Small sample which may mean results are not generalizable</p>	<p>Patient perspective. Clearly distinguished between PPD and PPC Methodology of asking questions about end of life after rapport was built is relevant to this study.</p>
<p>Discussing preferred place of death with patients: staff experiences in UK specialist palliative care setting  Field, A., Finucane, A and Oxenham, D. 2013  A UK study</p>	<p>Qualitative semi-structured interviews to explore clinicians experiences of discussing end of life with patients (n = 6). Interpretive Phenomenological Analysis was used to analyse the data.</p>	<p>Staff think end of life conversations with patients as important, even if the PPD is not elicited. Such conversations can be difficult. There is a need for clear language and the avoidance of euphemisms for "death". Staff should aim not to be paternalistic.</p>	<p>Method relevant detailed, with validity checks &amp; reflexivity. Ethical approval reported. Recruiting cross-section of staff adds strength to results. The design pre-supposes necessity of anticipatory planning and staff skills &amp; confidence</p>	<p>Clinicians views. Makes the case for enabling the patient voice. Demonstrates this is possible. Talking PPD is seen as important – not merely eliciting information. Consider how this fits with patients' views and experiences.</p>



## 8.5 Discussion of the Literature

The theoretical concepts of the emerging theory which were expressed in Core Category, 'Enabling The Patient Voice to be Heard', provided the framework for the review. These were:

- Tools and Skills to Enable the Patient Voice to be Heard
- Opportunity to Speak
- Permission to Speak
- Support

In the emerging GT, one component in assisting in the facilitation of the voicing and hearing of patient views on PPD in the GT was the varying degree of tools and skills possessed by patients, carers and staff. One key area identified within this concept of tools and skills was staff training.

Staff training featured in literature: in particular the need to improve the quality of discussions between clinicians and patients on end of life matters was noted. Several papers called for more and better training in communication skills (Murtagh and Thorns, 2006; Barclay and Maher, 2010; Munday, Petrova and Dale, 2009; Thompson-Hill et al., 2009 and Field, Finucane and Oxenham, 2013). It was recognised that high quality end of life care is dependent on skilled and sensitive judgements from healthcare professionals (Murtagh and Thorns, 2006; Barclay and Maher, 2010). It was evident that across the different settings in which people die, training in specific end of life communication skills varies widely (Munday, Petrova and Dale, 2009). Some hospital staff felt ill-equipped to initiate and undertake end of life conversations with patients in a competent and timely manner and one which would

not cause distress to patients (Thompson-Hill et al., 2009). This echoed the view of the emerging GT, that effective staff training has not been consistently achieved and that this rather sporadic nature of current training can impact negatively on whether or not patients are able to express their end of life wishes.

Field, Finucane and Oxenham (2013), however, related a successful example of how the required communication skills relating specifically to end of life planning had been acquired amongst a certain group of hospice staff. Elements of this success included allowing a passage of time for skills to be practised in the clinical setting until these skills became easier to implement. This accrual of experience subsequently increased confidence in the workforce when approaching discussions on end of life. Learning from peers, shadowing more experienced practitioners and sharing skills at team meetings were helpful in building staff expertise and confidence, as was embracing the notion that end of life care planning was an important and vital part of the professional role.

This positive example of specific staff training challenges the picture portrayed of the hospice in the GT study, where there is no specific training in end of life planning communication skills. This contrasting portrait of the state of provision for schooling in these particular skills indicates that such training is context dependent. The fact that the literature is beginning to report positive examples of relevant and specific staff training is supportive of the emerging GT which identifies this as important.

The emerging GT considered whether or not the skills accrued in training were actually deployed by hospice staff as pertinent to 'Enabling The Patient Voice to be Heard'. Much of the literature reported that staff inferred their patients' wishes from general conversations

and in some cases such inferences had been recorded in the patient record, sometimes without the knowledge of the patient (Holdsworth and King, 2009). This practice raises questions around consent, for example the patient should be made aware that a choice has been recorded in case they wish to change it. Arguments about patient-led care do not offset the ethically questionable practice of recording and potentially acting on a preference of which the patient was not aware (Holdsworth and King, 2011).

A small portion of the literature, however, identified a more direct approach by staff. A qualitative study amongst hospice clinicians, which explored the staff experience of discussing preferred place of death with patients, found that staff were able to successfully discuss this topic with patients in a direct and open way (Field, Finucane and Oxenham, 2013). In particular they noted the critical importance of using clear language and the avoidance of euphemisms for the words 'death' and 'dying'. The authors of this study concluded that although potentially difficult, if staff believe that advance care planning is important and beneficial, they do prioritise and develop strategies which enable them to discuss PPD in an effective, patient-centred way.

Whilst the literature depicts a developing landscape with regard to the deployment of skills, it is largely supportive of the emerging GT concept that the degree of deployment of such skills by healthcare professionals, can directly affect the process of enabling the patient voice.

In addition to the need for healthcare professionals to possess good communication skills, the emerging GT postulated the need for good practice in the mechanics of actually collecting patient preferences. In particular, the emerging GT proposed that, awareness of documentation in which to record patients' wishes was important and that this applied to

patients, hospice staff and carers. The emerging GT suggested that a greater awareness of the documentation had the potential to increase the likelihood of staff actually engaging in collecting patient preferences and would improve the prospect of services more accurately meeting preferences.

Issues around awareness of documentation appeared in the literature. Two tools which could assist in eliciting, documenting and reviewing the patient preference regarding end of life care, which had been piloted in the field appeared in this literature review (Holdsworth and King, 2009; Thompson-Hill et al., 2009). Thompson-Hill et al. (2009), emphasised the importance of gaining the support of senior management and clinicians in introducing their tool into the acute hospital setting and raising levels of awareness of such a tool's usefulness. They suggested that making the tool available on the central computer system would enfranchise all staff across the healthcare economy including those working out of hours, ambulance staff and primary care staff. Issues of accessibility and user friendliness would also be enhanced by education and awareness training for all staff in this hospital setting.

Holdsworth and King (2009) found that using appropriate terminology was paramount in making a tool acceptable in the field. In the developmental stage of their tool, it was decided to change the phrase Place of Death to Place of Dying, at the behest of patients and carers in the study. This was interesting as it demonstrated that it is possible to find an acceptable phrase for end of life which is both frank and clearly non-euphemistic. This study advocated for a standardised approach with the same language, timing, and criteria being used for asking about preferences. This would ensure equitable treatment of all patients; that choices are clear to all involved; that decisions are not taken because of a lack of options.

It is clear that tools and mechanisms to aid the collection of patient preferences are now appearing in the literature and that issues around awareness-raising and the utilitarian value of such tools are being brought into focus. That awareness of such tools can positively contribute to the patient voice being heard, is in agreement with the emerging GT, although the ultimate effectiveness of such tools is directly related to the rate of future take up by institutions caring for terminally ill people.

The literature did not address patient and carer awareness of documentation and the ways in which this affected outcomes relating to the recording of patient wishes. The emerging GT, however, suggested that familiarity with the documentation by patients and carers, could impact on patients' thinking about their end of life plans and on their subsequent action regarding documenting wishes.

Another important facet of tools and skill to enable the patient voice presented in the GT was the patient ability to discuss their PPD. In contrast to concerns expressed elsewhere in the literature, that talking about end of life concerns will cause undue distress to terminally ill people (McCarthy and Addington-Hall, 1997; Elkington et al., 2001; Lynn et al., 2000), several papers demonstrated that concerns around undue anxiety are not generally shared by terminally ill patients.

Shah et al. (2006) conducted a study amongst people with a variety of end-stage illness and doctors treating people with terminal diagnoses. This study compared patients' and professionals' views on estimations of prognosis; perceptions of the seriousness of the illness; and acceptability of doing such sensitive research, amongst people with end-stage illness. Although preferred place of death did not feature directly in this study, the methodology was

direct and searching in its approach to asking questions about end of life. Vignettes which described various day-to-day living scenarios across the illness trajectory were employed as a means by which patients could evaluate their current health status and think about the future, including estimated life expectancy. All the patients in the study were well aware of their prognosis and did not object to answering direct questions about end of life.

In a study amongst home alone terminally ill people which aimed at eliciting patient preferences for place of care and death longitudinally and reporting on the congruence between preferred and actual place of death, Aoun and Skett (2013) also demonstrated patient amenability to discussing end of life matters. In this study, a semi-structured questionnaire was used to ascertain the end of life preferences at two points along the illness trajectory. Participants were specifically asked to designate their preferred place of care and their preferred place of death, thus illustrating patient ability to answer straightforward and direct questions on this matter.

The willingness and ability of patients to discuss end of life matters was further confirmed by Jones et al., (2011), in an exploratory randomized controlled trial of oncology and hospice patients' perceived ability to engage in advance care planning discussions. This trial asked patients to complete an advanced care planning discussion with a healthcare professional and then to evaluate this experience by means of a questionnaire. Due to randomised controlled trial methodology, not all participants completed the advanced care planning discussion: 51% of participants, opted for the discussion; 35% were happy to be randomly allocated and so had no objection to having the advanced care planning discussion; and only 15% of participants chose to opt out. In this trial, then, 86% of participants were willing to engage in an end of life discussion. In addition, this study measured rates of anxiety and depression

arising as a result of taking part in this trial. Significantly, it demonstrated that in the lived experience of patients who had engaged in an end of life discussion, undue anxiety or depression were not caused.

Terry et al. (2006), demonstrated particular difficulties with patients and carers discussing end of life matters. This study showed that the patient desire to discuss this issue with their carers was not unanimous. This study reported on tensions between patient and carer wishes, to the extent that some patients clearly wanted their views to be considered in isolation from any views expressed by their carers and vigorously upheld their right to choose whether or not to discuss their wishes with their carers. This was in direct contrast to carers in this study who appealed to family authority over patient desire for privacy, arguing that duties arising from their status as carers outweighed the patient right to privacy and autonomy. Clearly, this issue can potentially be a source of tension within the family situation of the dying person. Family tension was also evidenced by Luijkx and Schols (2011), who found that the designation of a preferred place of death is usually arrived at by negotiation between family members. This study showed that a pragmatic approach is often taken in coming to a decision wherein factors such as carer disposition towards supporting someone at the end of their life is a major consideration. In the case of home being nominated as the preferred place of death, the presence of a co-habiting partner was seen as essential.

The literature, then, largely supports the view that patients are able to discuss end of life matters and potential issues with regard to negotiations within families regarding PPD were noted. In the main, this supports the view of the emerging GT, that the extent to which patients are willing and able to discuss PPD affects whether the patient voice is heard.

Indeed, the emerging GT presented a rather mixed picture of patient readiness to discuss this matter, with different patients exhibiting a range of abilities with regard to talking about PPD. It also puts forward the view that a resounding refusal to talk about PPD was a valid expression of the patient voice. The notion of the silent patient voice is not represented in the literature.

Another component of the emerging GT was how opportunities to speak about PPD were made available to patients and how patients made use of opportunities. A patient's state of health could influence this.

Barnes et al., (2007), conducted a focus group study amongst oncology and palliative care patients on issues around discussing end of life, and concluded that discussions should not be initiated too early along the illness trajectory, while Jones et al., (2011), found there were suggestions that appropriate time for this discussion, was after the recurrence of disease or when the prognosis became poor. Similarly, in a focus group study amongst patients to identify issues around talking about end of life, it was suggested that the appropriate timing for such a conversation would be when death is imminent (Holdsworth and King, 2011).

This contrasts with the view of this emerging GT, in which patients, carers and staff argued that end of life conversations were easier to conduct and more effective when the patient was relatively well. The emerging GT also made the point that there is a danger that the patient voice will not be heard if the attempt to have this conversation is left until the patient is too ill to engage in such an emotionally demanding task.



The literature also noted that postponing such discussions until the virtual end of life had important implications for healthcare providers regarding forward planning. For example, it may be important to elicit early on whether a patient has a preference to die at home, in order to allow enough time for service providers to source and deploy the relevant support to facilitate this. It is possible that explaining this rationale to patients can have a positive effect on ensuring timely discussions (Murtagh and Thorns, 2006; Holdsworth and King, 2011).

The emerging GT recognised that patient decisions sometimes changed along the illness trajectory and therefore raised the idea of reviewing patient wishes on subsequent occasions to ensure the patient's current wishes were being captured. In agreement with the emerging GT the literature recognised that, frequently, patients' end of life preferences are dynamic in nature and therefore, some patients voiced concern around "setting things in stone", that is, patients desired to retain the facility to record any change of mind they may have, even when their view had been documented in the patient record. The provision of opportunities for patients to have end of life discussions on a number of occasions would allow for ascertaining and recording any changes in the patient preference (Munday, Petrova and Dale, 2009; Holdsworth, 2011).

Part of the emerging GT concept of patients having the opportunity to speak, was the notion of 'finding the right moment'. There was no agreement amongst participants as to when this time might be, but more an idea that such a time existed for each individual. Another way of expressing this concept is 'the individual patient's readiness to talk about PPD'.

The literature concurred that amongst patients there was an explicit desire that the healthcare professional engaged in this task should respond positively to patient cues and respect the fact that some patients may not feel ready or able to engage in end of life discussions. Interestingly, there was some suggestion that engaging in end of life discussions can enhance a sense of control over one's own destiny for palliative and oncology patients (Barnes et al., 2007).

Patient readiness to talk was also addressed in the literature by the presentation of the case for a stepped approach to end of life discussions whereby the topic is visited and re-visited and may become part of the routine medical consultations (Clayton, Butow and Tattersall, 2005; Holdsworth and King, 2009; 2011). Patients said they would find it easier to talk about their preferences if they were warned in advance that they would be asked about their end of life wishes. This prefacing of information could be given during the first encounter with the hospice, either in a home visit or on admission, in preparation for the next encounter with hospice staff (Holdsworth and King, 2011). For example, at the first time of asking, the patient may decline the offer of a discussion, but when asked at a subsequent time, they may have processed their thinking around their end of life wishes and may now be suitably emotionally and physically able to converse about these matters.

Therefore, concurring with the emerging GT, the literature makes the case for building flexibility into the approach to ascertaining the PPD. Such a flexible approach would be better able to respond appropriately to the individual needs of each patient and the complications caused by the unpredictability of their lifespan.

It would seem then that although neither the literature nor the emerging GT suggests a specific optimal point along the illness trajectory at which such a discussion should take place, there is agreement that individuality plays a major part: that some patients may want to discuss everything early on whilst others may need to travel at a slower pace, requiring time to come to terms with the profundity of the experience they are living through (Murtagh and Thorns, 2006).

The emerging GT concept of permission to speak encompassed a range of views from those patients who felt they did not need anyone's permission to those who had not spoken about their PPD due to feeling they had not been granted permission to do so.

Whilst there was no literature depicting patients spontaneously and vociferously declaring their PPD as a demonstration of not needing permission, one study in the review showed that some people do not find end of life discussions particularly burdensome. A study amongst healthy older adults on end of life discussions (Van Leuven, 2011), looked at the beliefs, attitudes and behaviour of older adults on end of life planning and showed that the majority were not averse to thinking about the end of life. Adults who viewed themselves as healthy had advance care plans in place and perceived making plans for death as a culmination of a good life and as a manifestation of successful ageing rather than something to be avoided or postponed. In contrast, those who evaluated their health as fair or poor eschewed conversation and planning about end of life, citing reasons of being too busy maintaining day to day living or feeling it was inappropriate to talk about at this stage in their life.

This study suggests that conversations about end of life plans are now more commonplace in wider society than previously. It is unclear whether this is related to end of life discussion

trends within the hospice and terminally ill world, but provides a glimpse of how the literature is beginning to address discussing end of life conversations within the context of the general population. Moreover, it supports the emerging GT view that some people do not need to gain permission from some outside agency, be that family members, healthcare professionals or society at large, in order to speak about their end of life wishes.

However, the emerging GT also holds that some patients felt they were granted permission to speak from hospice staff. Interestingly, the literature showed that it was broaching the subject of end of life which presented the greatest hurdle for staff: healthcare professionals felt much more able to engage in discussions if the subject was raised by the patient. In general, staff considered this to be the correct tactic within an approach to practice which is careful to avoid causing harm and distress to patients. With this backdrop, the literature depicted a scene wherein it was rare for healthcare professionals to broach the subject of end of life with their patients by asking about this matter directly. Rather, waiting for the patient to initiate a direct conversation on this matter was the preferred option, followed by a scenario in which the patient alludes, perhaps tentatively, to the possibility of their death, which was then seized upon as an invitation for the healthcare professional to progress the conversation towards planning for end of life. (Clayton, Butow and Tattersall, 2005; Munday, Petrova and Dale, 2009).

In contrast to the emerging GT, then, the literature seems to depict patients granting staff permission to talk about end of life matters. However, it could be that patients interpret staff willingness to respond positively to their overtures of talking about PPD as the mechanism by which staff grant them permission to open up this topic for conversation. It could be that

patients have tried to open such conversations in like manner with other people, family members, for example and have found the topic closed down at that point.

Indeed the emerging GT evidenced a range of views on the part of family members, with some welcoming and supporting the patient desire to have their voice heard whilst others presented barriers to this. The literature addressed the carer perspective on place of death in a retrospective study which looked at bereaved carer satisfaction in this regard.

A Department of Health national survey of bereaved people asked those who were bereaved whether their associated deceased people had expressed their preference for where they would like to die (DH, 2012). This study found that less than half of the deceased people were reported to have expressed a preference for where they would like to die. Although half of the bereaved people answering this question felt that the patient had enough choice, a quarter did not. Despite this, the large majority of respondents (82%) felt that the patient had died in the right place.

The view that even when patients did not express their preference, carers were satisfied with the end of life experience of their patient, including the location of death could, arguably, suggest that making preferences for place of death explicit, may not be necessary (DH, 2012; Holdsworth and King, 2009). It is unclear whether this perception might encourage or discourage open conversations on preferred place of death and therefore whether or not this could potentially act as a barrier to the patient voice.

The emerging GT concept of support concerned the level of support available to patients to enable their views on PPD to be heard. Hospice staff were perceived as willing listeners with the necessary skills to facilitate such discussions.

The literature, however, portrayed a more complex picture of how healthcare professionals performed this role. Healthcare professionals reported that they did not find this an easy area of practice, feeling they lacked confidence in talking directly with patients about the end of their lives (Barclay and Maher, 2010; Thompson-Hill et al., 2009; Holdsworth and King 2009; Munday, Petrova and Dale, 2009; Murtagh and Thorns, 2009; Holdsworth and King, 2011). In a study amongst GPs and community nurses, perceived levels of difficulty ranged from “generally not easy” to “outright difficult” (Munday, Petrova and Dale, 2009).

Barclay and Maher (2010), suggested that physicians had a whole range of neuroses about end of life conversations with patients. These included difficulties associated with the imprecision of prognostication, the desire to avoid taking away patients' hope, and the seeming inability of physicians to resist a medical activist approach, characterised by a belief that there is always another medical treatment to be tried. These all play their part in healthcare professionals' experiencing end of life conversation as an arduous task.

In addition, many hospital specialists avoid raising the topic of end of life care, believing that the primary care setting, in which the patient has a longstanding relationship with the healthcare professionals, is a more conducive setting for such an encounter. A study which piloted a new tool to enable hospital staff to record patients' end of life care preferences (Thompson-Hill et al., 2009), confirmed hospital staff's lack of confidence in this area. Conversely, primary care staff often assume that hospital staff will already have started the conversation with patients because, in their opinion, that would be most appropriate context and therefore primary care staff avoid this topic with patients. This can easily result in a situation where no healthcare professional takes responsibility for ensuring that patients are

provided with the opportunity to discuss end of life matters, should they so wish (Barclay and Maher, 2010).

It was interesting that the literature showed a general lack of confidence amongst healthcare professionals regarding assisting in the patient voice on PPD being heard and which may, in some cases inhibit the expression of end of life wishes. This contrasts with the emerging GT notion of staff as supportive and highly skilled in this area. However, the general negative view portrayed by the literature includes hospital and primary care staff in its purview, whereas the situation for hospice staff, within the exclusively palliative care setting may not be so negative. Indeed examples of good practice are beginning to appear in the literature, such as the study by Field, Finucane and Oxenham (2013) which reported the upskilling of hospice staff.

The emerging GT purports that documentation supports 'Enabling The Patient Voice to be Heard' by acting as a prompt to ensure that patient preferences are ascertained and recorded and also by bestowing legitimacy on the notion of recording the PPD.

The literature reported on two new tools for recording PPD (Holdsworth and King, 2009 and Thompson-Hill et al., 2009). The former was to be used within the hospice setting and the latter had been piloted in an acute hospital, but was due to be rolled out across all settings in the local healthcare economy, including the primary care and the hospice. The fact that new tools and mechanisms to aid in the collection of patient preferences are now appearing in the literature demonstrates a growing concern to positively aid the patient voice being heard. Whilst this echoes the emerging GT concept of support for 'Enabling The Patient Voice to be Heard', it is noteworthy that in both studies, the recording of PPD as standard practice had

not yet been established. Therefore it is not possible to assess how much support existing documentation affords the enabling of the patient voice being heard in the current context.

Regarding how recording the PPD confers legitimation and hence supports the patient voice, Barnes et al. (2007), found that that patients were more likely to talk to their family and friends about their end of life wishes if they had completed the advanced care planning intervention. Seemingly, for these patients, the subject had not been previously discussed with their carers; the reasons for this are unknown. This suggests the potential pivotal role of recording one's PPD in triggering wider discussion within the patient's social circle. Whilst this resonates with the notion of legitimation put forward in the emerging GT, this was not a major theme in the review.

The emerging GT considered the positive perception of the notion of choice as part of the concept of support. The idea here was that in UK society, choice is perceived as a social good which is somehow of benefit to the population. More particularly, in recent years the UK government has shown great commitment to choice in healthcare (e.g. NHS Act (DH,2006); Health and Social Care Act (DH,2001); NICE Guidance on Palliative Care (NICE, 2004); End of Life Care Strategy, (DH,2008). Choice perceived as something positive is therefore supportive of 'Enabling The Patient Voice to be Heard'. Issues around choice were seen in the literature.

In a study about the concerns of dying hospice patients (Terry et al., 2006), in which semi-structured interviews ascertained the views of participants, it was clear that far from being reluctant to discuss end of life, patients were anxious to ensure that their voices were clearly heard. There was concern that the autonomy of the dying patient should be recognised and



respected: that patients' views should be seen as distinct from family wishes, and that patients largely wanted to maintain control over decision making regarding their healthcare, including end of life provision. Many sought factual information regarding the physical process of dying, again underlining the desire to confront rather than deny the inevitable fact that their death would happen in the near future.

Similarly, a study by Clayton, Butow and Tattersall (2005), in which patients took part in focus groups to give their views about when and how end of life discussions should occur, showed there was broad agreement amongst patients that it was appropriate and important for this issue to be made accessible. Pevey's (2005) in-depth interview study, amongst hospice at home patients evaluating the care they received, reported that desire of patients to openly talk about one's death was prevalent in this group. In this study many patients characterised the open discussion about death and dying, including planning for end of life with hospice staff, as an important way in which the hospice provided comfort. This was especially important if the patient's family and friends were not open to a discussion on end of life matters.

Furthermore in a study by Murtagh and Thorns (2006), amongst hospice patients, which explored palliative care patients' preferences for information and their preferences for involvement in decision-making about their future care, it was found that eliciting patient preferences improved patient satisfaction and doctor confidence.

Choice in the matter of PPD, of course, includes the option to decline the offer of an end of life conversation. This was reflected in the literature which evinced less enthusiasm for total frankness on end of life matters. Some of this reticence related to care at the end of life:

some patients found the enforced intimacy of hospice care distasteful and some firmly rejected the invitation to discuss the psycho-social aspects of dying, regarding this as deeply personal (Terry et al., 2006). The patient having the opportunity to reject an end of life discussion also featured in the study by Clayton, Butow and Tattersall (2005), in which patients gave their views about when and how such discussions should occur. There was a clear opinion that the patient should be given the option not to hear the prognosis and discuss end of life if that was their wish.

The literature, then, supports the emerging GT view that patients being offered choice regarding their end of life healthcare is generally perceived as positive. Patient access to end of life discussions was largely seen as part of this 'choice is good' discourse. However, to be truly supportive of enabling the patient voice, choice must always include the right to decline.

The emerging GT noted another societal trend as part of the concept of support, that is the perception that talking about death is taboo in UK society. Such a taboo is not supportive of palliative patients talking openly about their plans for care at the time of their death and breaking societal taboos can be difficult. The emerging GT suggested that invitation to have one's PPD recorded is supportive of 'Enabling The Patient Voice to be Heard' above the often, unspoken, societal instruction to keep quiet about this.

The literature illustrated taboo attitudes to talking about death with regard to particular difficulties with terminology and euphemisms. In Holdsworth and King's study (2009) which charts the development of a tool to aid in the collection of patient preferences, at the design stage, the patient participants requested that the phrase Place of Care for *Death* was replaced by Place of Care for *Dying*. Whilst this does not connote the deployment of indirect

language, the avoidance of the word death suggests a certain softening of language. The patient preference recording tool reported by Thompson-Hill et al., (2009), avoided the word *Death* in favour of the word *Care*. It was unclear why this term was used, but this is in stark contrast to research which calls for direct and clear language (Holdsworth and King, 2009; Field, Finucane and Oxenham, 2013) and studies which demonstrate the words care and death convey different meanings to patients (Agar et al., 2008).

In the Field, Finucane and Oxenham study (2013), this problem had been faced by the development of specific techniques for handling such emotionally laden words as *death* and *dying*. This included using a stepped approach whereby carefully worded-phrases would first be utilised to signpost to the patient that this was an opportunity to talk openly about death and dying and to provide an opportunity to gauge the patient readiness for this. Additionally, staff would deliberately emphasise to the patients, the positive aspects of early planning for death.

The literature, then, showed a varied scene regarding whether the taboo around talking about death was successfully broken within end of life provision. There were some examples of best practice regarding the development of how to talk about death and dying in a direct and non- euphemistic manner as a means of breaking society's taboo, with other examples of showing the avoidance of openly talking about death and dying. This mixed picture with regard to end of life practice supports the emerging GT view that this taboo is still evident and exercises power over whether or not the patient voice is heard.

## **8.6 Summary**

This chapter has presented an account of the extent to which the concepts of the emerging grounded theory were found in the substantive literature review. The extent to which my emerging theory supported, contradicted or extended current knowledge has been considered. Chapter Nine will present the Grounded Theory: 'Enabling The Patient Voice to be Heard'.

## **Chapter Nine      The Grounded Theory: 'Enabling The Patient Voice to be Heard'**

### **9.1      Introduction**

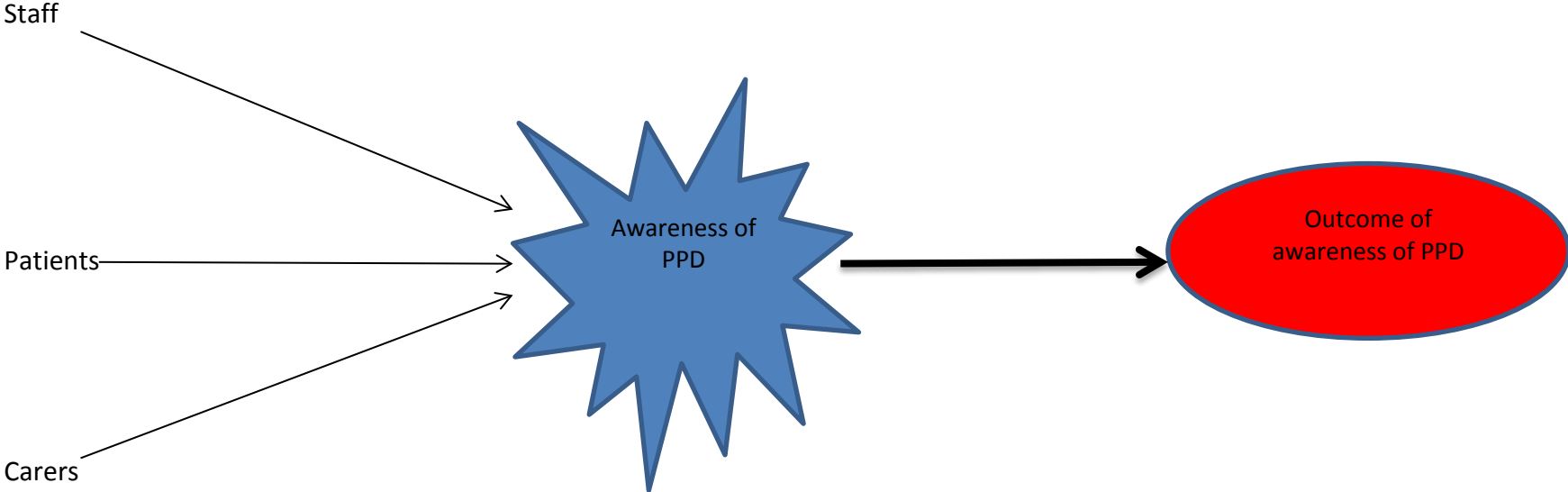
This chapter presents the substantive grounded theory: 'Enabling The Patient Voice to be Heard'. The grounded theory has conceptual and explanatory power to portray a theoretical interpretation of the latent pattern of behaviour (Holton, 2007) within the social setting of the study, that is, one UK hospice.

### **9.2      Overview of the Grounded Theory**

Starting from the basic analytical work which had produced seven categories and a core category, the search for an eventual possible integrative theory, was undertaken. Initially, the usefulness of employing a type of axial coding was considered. Strauss and Corbin (1990) used axial coding to relate categories to subcategories and employed a pre-set structure known as the Paradigm Model as a means of achieving further conceptual thinking. The imposition of such a pre-set structure as a frame which could be applied to this research was rejected in order to preserve the particularity of my unique analytical interpretation. However, the basic idea contained within the Paradigm Model was used as a guiding principle to progress analytic thinking. The basic idea in this model is of that of moving from causal condition to phenomenon.

So for this study, the causal condition was the fact that patients, carers and staff at the hospice become aware of the possibility for the patient to consider their PPD. The phenomenon towards which the analysis moved was finding the outcome of patients becoming aware of the possibility of considering their PPD. This outcome included the experience of all the research participants; that is patients, informal carers and staff. The movement from causal condition to phenomenon is illustrated in Figure 8.1

**Fig 9.1 Generation of Grounded Theory: From Causal Condition to Phenomenon**



With this notion as a guiding principle, some questions were formulated in an attempt to illuminate any connecting threads. The first question was almost identical to the original research question: What is this hospice's experience of preferred place of death? Building on thinking around that question, the second question was: What did participants identify as key influences on their experience of PPD? A third related question was: From the data analysis what concepts are identified as contributing and influencing the experience and process of PPD? This thinking, enabled progress towards the postulation of an emerging theory, namely: 'Enabling The Patient Voice to be Heard'.

Therefore, as a means of integrating all the codes and categories and offering an explanatory theory of the data, one core category was selected to form the grounded theory: 'Enabling The Patient Voice to be Heard'.

### **9.3 Development of the Grounded Theory**

'Enabling The Patient Voice to be Heard' suggested itself as a potential category early on in the data analysis. This was confirmed across the different data sets of focus groups, patient interviews and carer interviews as the analysis progressed. In keeping with the constructivist grounded theory methodology of this study, all analytic ideas and inspirations were noted from the very first stages of data collection. Application of the constant comparative method meant that the relationships between the different levels of conceptual abstraction were retained in the analysis. Hence Figure 9.2 conveys the relationship of the core category to earlier stages of the analysis, that is focussed codes and the various categories. This information is presented in table form in order to give a clear overview of how the theory came about and in particular to demonstrate that it is grounded in the data.

**Figure 9.2 Development of the Grounded Theory: Focussed Codes and Categories**

<b>Focussed Codes</b>	<b>Potential Categories</b>	<b>Grounded Theory</b>
Promoting patient autonomy	Patient autonomy	Core category: 'Enabling the Patient Voice to be Heard'
Family Issues	Barriers and access	
Communication Issues:	Enabling the patient voice	
<ul style="list-style-type: none"> <li>• Patients and staff</li> <li>• Staff and families</li> <li>• Patients and families</li> </ul>	Power to engage with PPD	
Concerns re service provision:	Mediation	
<ul style="list-style-type: none"> <li>• Patients</li> <li>• Staff</li> <li>• Carers</li> </ul>	Communication as empowerment	
Medical factors	Safe space to engage with PPD	
Documentation		
Learning about PPD		
Engaging with PPD		
Reflecting on talking about PPD		

The tabular form, however, has limited capacity to convey the dynamic interplay between codes and categories which produced the eventual theory. It may appear that the process of theory generation was rather neat and straightforward, static, even. This was not the case, however, as the process entailed a great deal of moving back and forth between codes and categories in order to check the robustness of emerging conceptual ideas and the full explication of categories.

This constant comparison of data and conceptual thinking resulted in the generation of a complex network with linkages between codes and categories, as focussed codes were



shown to support the emerging categories. For example, the code Reflecting on Talking about PPD related to three categories, namely, Safe Space; Power to Engage with PPD and Mediation. These categories were linked to six other codes, namely, Documentation, Communication Issues; Family Issues; Promoting Patient Autonomy; Learning about PPD and Engaging with PPD. In turn, each of these six codes were linked to other categories and codes within this complex network.

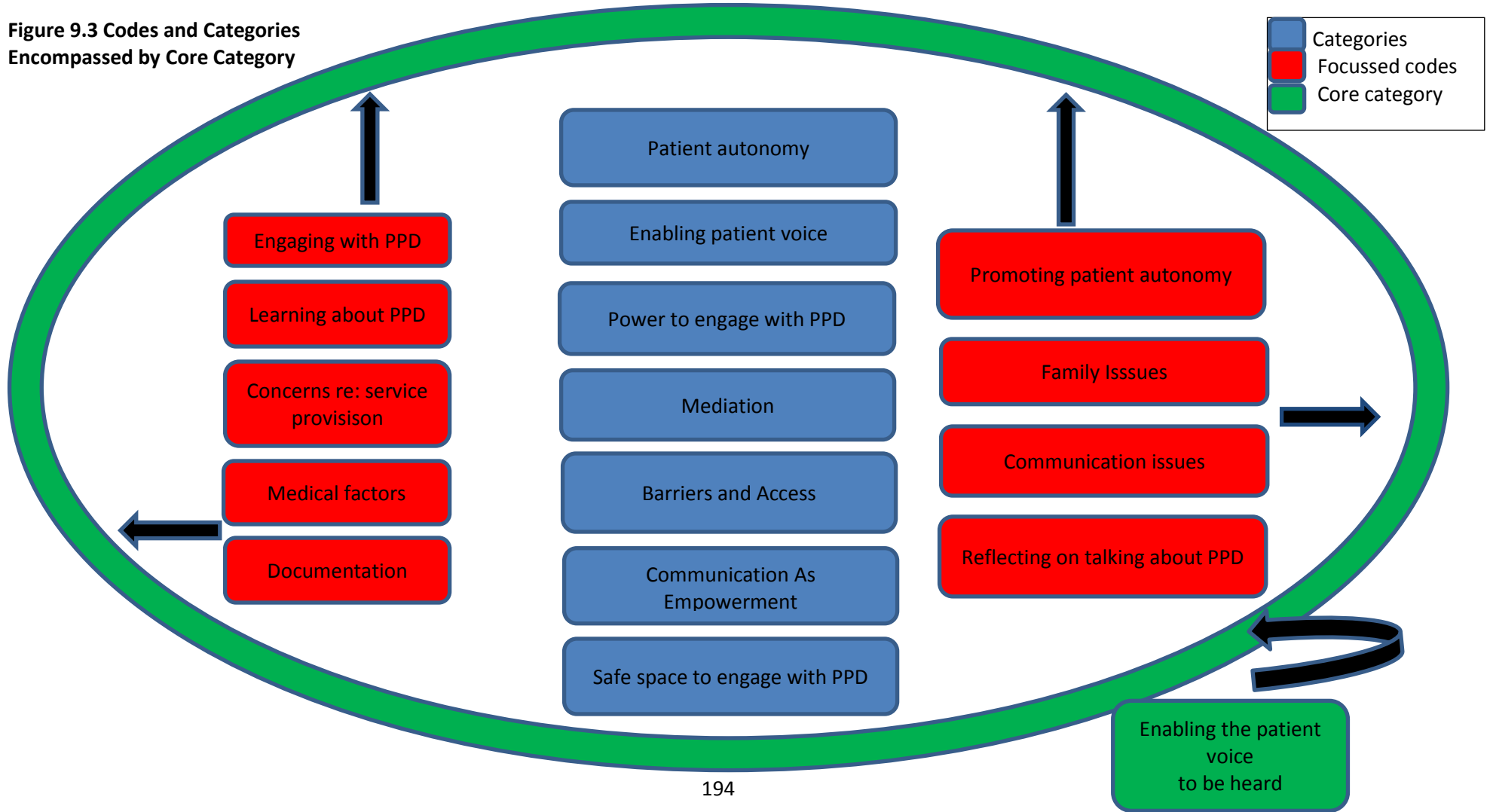
The conceptual thinking which happened during the generation of this network greatly aided the articulation and selection of the core category of this theory. The core category was eventually selected because it connected, in a theoretically satisfying way, all of the categories in the network. Within the core category of 'Enabling The Patient Voice to be Heard', all the categories integrate together to form the abstract grounded theory of this study (Charmaz, 2006; Clarke, 2005).

The use of the term *core* category is interesting because the core category within this theory does not function as an axis around which concepts and categories turn (Strauss and Corbin, 1990). The core category functions, rather, as a conceptual shell which encapsulates and encompasses all the social processes present in the data. As an encompassing shell, 'Enabling The Patient Voice to be Heard' acts as a container or envelope of the theoretical explanation of this research: it gives the research form and expression. In addition, just as an egg shell holds all the different internal parts of the egg together, and in that respect is organically related to all the different parts, this grounded theory holds all the parts of the research together and is integrally related to all the component parts. Although this theory does not adhere to a Glaserian grounded theory approach, his notion that a core category will have 'grab', will be hard to resist, and that researchers

will see their core category everywhere in their research (Glaser, 2007) is apposite.

The fact that the eventual core category was suggested quite early on during the data analysis phase of the research is a good illustration of how the constant comparative method was utilised throughout the data collection/analysis of this study. Figure 9.3, which depicts the codes and categories which make up the core category, illustrates that the constant comparative method was used at all stages of theory development including the early stages, as several arrows lead from certain focussed codes directly to the core category. It was considered important to depict this not merely as a faithful rendering of the process of theory building, but moreover as a strengthening and confirming of the selection of 'Enabling The Patient Voice to be Heard' as the core category of this grounded theory. Figure 9.3 also clearly illustrates how all the codes and categories are encompassed and contained within the core category.

Figure 9.3 Codes and Categories Encompassed by Core Category



#### **9.4 Credibility of the Grounded Theory**

An overview of the ways in which the GT fits credibly with the data and the reviewed literature is now offered, as a means of demonstrating my commitment to producing findings within which participants would be able to recognise the meaning that they themselves gave to their experiences (Holloway and Wheeler, 2010).

The focus group participants identified one key role for hospice staff as that of assisting patients to ensure their voices were heard regarding their healthcare and treatment choices as a means of supporting patient autonomy. Good communication between staff and patients was seen as key to this role being effective and positive. Staff stated that good communication assumed intense significance when attempting to facilitate end of life care discussions. They cited training courses in effective communication skills in addition to on-the-ward peer training as being supportive of their efficacy as competent communicators around this highly sensitive subject. Opening discussions on PPD, supporting patients to think through and articulate their end of life care wishes and careful listening to what the patients said were all seen as important. The fact that this population of patients, that is terminally ill people, constitute a particularly vulnerable and marginalised group was clearly evident to the hospice staff.

Noting that hospice patients' life choices had been severely limited by their illness and symptoms, some staff saw patient autonomy and the right to make choices and express preferences in terms of social justice. Concomitantly, they perceived their role as that of advocate and enabler of patient autonomy. Staff also highlighted the power relationship between the possibility of choice in PPD and eventual outcomes. Staff stated their view that unless patients engaged with PPD and recorded their preference, they were

likely to end up dying in the local hospital either in an acute ward or in a corridor in the accident and emergency department.

Staff suggested that a further aspect which could influence whether the patient voice was heard or not, was the power dynamic existing within families. It was staff's experience that family members tended to panic and call for an ambulance as death approached. They felt that this was less likely to happen if patients and their informal carers had made specific plans regarding what to do at the end of life, which would probably not encompass the ambulance-to-A&E scenario. Good forward planning and the effective communication of wishes was viewed as an effective means by which the patient could maintain some measure of control over the circumstances and thus exercise a measure of power within this situation.

Patients in the study confirmed the significance of having their voices heard in a number of ways. The overwhelming majority in the study welcomed the opportunity to record their PPD and the one patient who declined still expressed her support of the facility for patients to do this if they felt this was appropriate for them. Many expressed relief at being asked to discuss PPD, some explained that family members found the subject too upsetting to discuss, which caused frustration and sometimes distress on the part of the patient. Others were concerned about causing distress to their close family and friends by broaching the subject with them, yet remained desperate to discuss this matter with someone who would receive their views.

For some patients just becoming aware of the notion of PPD was empowering. It was as if, until now, they did not know that they were allowed to consider where they might die and being given permission to do this felt empowering. Some patients described how they made

use of this power almost immediately, actualising their new awareness of PPD by recording their wishes as soon as was practicable, whilst for others this happened some time later. For example, one patient was made aware of the possibility of recording her PPD in the morning and had completed the paperwork by the afternoon, whereas another patient decided to take the paperwork home with her until she attended the day hospice the following week.

An interesting facet of 'Enabling The Patient Voice to be Heard' concerned how awareness of the opportunity to record one's PPD conferred choice on the patient. Patients in the study explained how they felt that it was within their power to choose to talk about PPD or to decline: as one patient eloquently expressed it:

*there's no persuasion by the staff here, it's your choice. (Patient Interview 1:235).*

Patients expressed the view that society at large did not encourage or sanction open conversations about death in general and certainly not about PPD, which was also a cause of potential frustration and anguish. Concerns about future care and end of life service provision were also common and it was felt that being able to air their thoughts and ask questions regarding these matters was helpful and empowering. Some said that having talked about their PPD at the hospice gave them skills and tools to talk about this with their loved ones: this was similarly empowering.

Carers also welcomed the opportunity to discuss PPD and suggested that this could assist them in supporting their patient's wishes. Neither carer in the study had heard their respective patient's views on this matter but were anxious to do so, considering this to be a positive and potentially empowering action for patient and carer alike. They also felt that

society at large could benefit from hearing hospice patients' voices more clearly and freely.

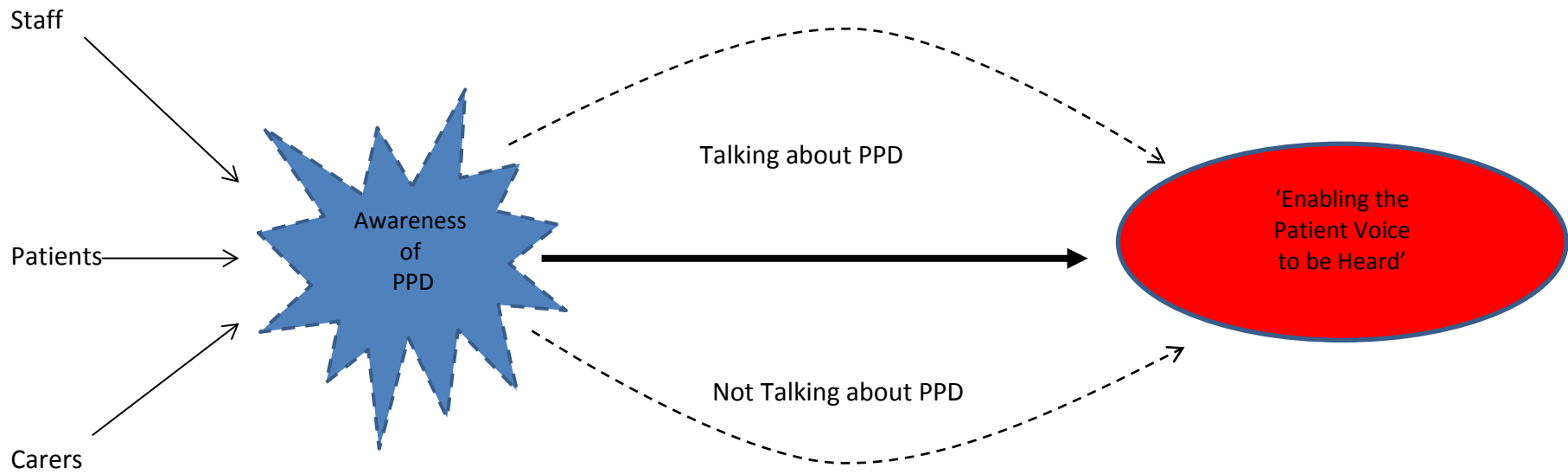
In a similar manner to their respective patients, the carers had real concerns around service provision at the end of the life of their loved one. Moreover, they suggested that hearing the patient's voice now could help greatly in making practical arrangements for the future which would have a higher chance of success. They felt this would assist them in honouring their patient's wishes rather than guessing what they would have wanted. This thought gave comfort to the carers.

Interestingly, carers commented on their sense of a more subtle manipulation of power being made available to them through their awareness of the notion of PPD. Formerly they had assumed that the place of death of their associated patient would be outside their control as it would be determined by extrinsic factors such as bed availability and decisions made by healthcare providers as to the appropriate setting for death. They had assumed a reactive stance was their only option because it would be in their patient's best interest to passively accept the provision offered by "the powers that be". Being able to choose a place of death felt empowering as it offered the possibility of a more pro-active stance.

The above comments demonstrate clear resonance with the grounded theory.

The grounded theory, which integrates all the analysed data is presented in diagrammatic form in Figure 9.4.

Figure 9.4 The Grounded Theory: 'Enabling The Patient Voice to be Heard'





## **9.5 A Note on the Diagrammatic Representation of the Grounded Theory**

One key idea which informed theory building was that PPD is something with which hospice patients, carers and staff interact. PPD exists as both a concept and a phenomenon. As a concept, PPD exists in the realm of the mind as the idea or notion that one can think about one's preferred place of death. As a phenomenon, PPD exists as the concrete, observable fact that hospice patients can be offered the opportunity to nominate the actual place where they prefer to die. It is potentially part of the hospice experience for all who are part of that context and in particular it is potentially part of the terminally ill person's life story. As people react to the phenomenon of PPD, a certain social process takes place. The grounded theory explains the social process.

A related idea which informed the diagrammatic representation of the grounded theory was that the notion of process carries connotations of movement and action: as a process unfolds, things happen. Within the research topic itself there was a natural sense of movement or progression in that the research investigates what actions, if any, ensue when the participants were faced with the topic of PPD. Inherent in the research topic seemed to be a sense of 'What happens next?' This was particularly interesting in that many participants in the study became aware of the notion of PPD only when they came into contact with the hospice. They were then afforded the opportunity to interact with the topic and move towards some sort of conclusion.

This sense of movement and progression is illustrated on figure 9.4 by the arrows. For example the arrows entering and emerging from the first box Awareness of notion of PPD trace the progression of the research participants. The arrows entering the box depict how the research participants are already in motion, being engaged in the ebb and flow

of their own lives. At the point when their arrows impact the Awareness of Notion of PPD box they move into the dynamic social process of this grounded theory.

The figure also portrays the fact that this is not a uni-linear progression: there are different arrows different pathways which may be followed. For example one may go from Awareness of the Notion of PPD, along the Talking about PPD arrow to 'Enabling The Patient Voice to be Heard', or one may take the route through Not Talking About PPD and thence to 'Enabling The Patient Voice to be Heard'. It may be argued that a pathway which goes from Not Talking can also end in 'Enabling The Patient Voice to be Heard' because the patient may wish for their voice to remain silent.

It may seem as if there is an apparent contradiction here in arguing that a voice may be heard by keeping silent, but this may be understood in terms of the role of silence within verbal communication. Rather than an absence of positive communication, silence may be deliberately deployed as an efficacious strategy (Chasi, 2013). For example, silence may serve to preserve patient privacy, effectively preventing further undesired explorations of the topic (Neethling, 2008). Silence may be part of the patient's listening to and processing of information offered regarding PPD and they may choose to speak at a later date. The silent voice also touches on the debate regarding patient autonomy and societal perception of the patient as object or subject with capacity to choose to remain silent. With regard to end of life planning the NHS End of Life Care Programme (DH, 2014), clearly states that patients do not have to do any of these things if they don't want to. Taking up the option of a silent voice was borne out in the data in that some patient participants declined to state their PPD and neither carer had discussed this topic with their respective patients.

## **9.6 Summary**

This chapter has described the grounded theory and charted the thinking around its construction. Chapter Ten will present the discussion of the GT.

### 10.1 Introduction

This chapter presents the discussion of my Grounded Theory (GT); how it impacts the current landscape of end of life care and thus makes its own valid contribution to the knowledge base in this area.

### 10.2 The Patient Voice Being Heard

My GT, *'Enabling The Patient Voice to be Heard'*, suggests that the outcome of the hospice patients becoming aware of the notion of PPD is that their voices on this issue can then be heard. The idea of *Being Heard* is central to my GT. Within this understanding, it is reasonable to wonder by whom the patient voice is heard and whether this makes a difference to hospice patients, carers, staff and society at large.

As a way into discussing this, I offer the analogy of a classic thought experiment, which has been considered by scientists and philosophers over many years (Marsh and Furlong, 2002). This thought experiment ponders the following: if a tree were to fall on an uninhabited island, would there be any sound? One solution to this experiment is that the falling of the tree or any other disturbance will certainly produce vibration of the air, but if there are no ears to hear, there will be no sound, that is, it will not be heard. It would seem, then, for the thought experiment to be answered in the affirmative, hearing is required. 'Hearing' is defined as *the capacity to perceive sound* and 'sound' is defined as *something that is received by the ears* (Oxford University Press, 1976). Therefore, if the tree falls in an uninhabited area, there will be no sound: it will not be heard. However, if it were to fall in an inhabited area, it would be heard by people and therefore, it would make a sound.

Considering my GT, *'Enabling The Patient Voice to be Heard'*, as analogous to the thought experiment, the patient's articulation of their PPD is the tree falling to the ground. The

question raised by the experiment then comes into play: what is required for the patient voice *to be heard*? According to the logic of the given solution, ears are required, society's ears. Since, unlike the tree in the experiment, hospice patients do not live on uninhabited islands, but in society, ears abound. This raises questions around whether the patient voice being heard makes any impact on society and if so in what ways. After all, in the thought experiment the tree falls to the ground and a fallen tree changes the landscape.

### **10.3 How The Patient Voice Being Heard Impacts the Landscape of End of Life Care**

One aspect of society which could be impacted by my GT is the way in which society views talking about end of life issues. Patient voices on PPD being heard means that they will have talked about death and dying. During the 20<sup>th</sup> century it was often asserted that talking about death had become taboo in the UK. In everyday usage 'taboo' refers to something prohibited or forbidden by custom rather than by law. At the extreme, something which is taboo may be too terrible even to think of, or more commonly something which is not mentioned in conversation (Walter, 1991).

Thinkers such as Gorer (1965) have argued that death became a taboo subject in the early part of the 20<sup>th</sup> century when Victorian stylised mourning rituals were gradually abandoned and beliefs and moral values became varied and individualistic, as the modern age came into view. In this new pluralistic society, there was no agreed framework for a discourse about death. At the same time, the increasing success of medical science, with its revolutionary advances in antibiotic therapy, transplant surgery, diagnostic techniques and preventative medicine, meant that prolonging life, rather than preparing for death, became the dominant medical model.

Moreover, increasingly, when death occurred, it no longer happened in the family home, but in the clinical settings of hospitals and nursing homes and became the province of healthcare professionals rather than of family members. In these ways, death became somewhat removed from everyday experience and many people became largely ignorant of what death actually entailed. Indeed, part of the inspiration for the modern hospice movement grew out of the perception that the UK had become a death-denying culture. Therefore the hospice movement sought to reclaim death as a natural phenomenon and societal norm, rather than something to be denied, not talked about and hidden away (Saunders, 2005).

More recently, the view of UK society as a death-denying culture has been critiqued, as an alternative view has been put forward, which says that, death is, once again, becoming something we *can* talk about, (Zimmerman and Rodin, 2004). Walter (1991) for example has noted that no Sunday is without at least one newspaper discussing death, bereavement, hospices, or funerals and books and films on the topic of death and dying continue to proliferate. The developing field of bio-ethics, including discussions about the appropriateness of certain medical treatments for people approaching the end of their lives and the appearance of documents such as Advance Directives and Living Wills in which to record people's wishes in these matters, also indicates a greater societal engagement with discussions around death and dying (Cohen et al., 1997). Such observations contribute to the view that there is something of a revival of discussions about death, which represents a new and increasing attitude of death acceptance in western society (Zimmerman and Rodin, 2004).

However, the depiction of society's attitude to talking about end of life issues is more complex than one in which there is a universal embracing of open dialogue about death.

Whilst society may be showing a more accepting attitude towards discussions about death in general, talking about the specific death of a loved one, or one's own imminent death or the death of a patient whom a healthcare professional has cared for, remains emotionally upsetting for many people (Kellehear, 1984). To expect people, even those in the palliative care world, including healthcare professionals, patients and carers, to be able to speak about such deaths as easily as any other subject is unrealistic and arguably, undesirable (Zimmerman and Rodin, 2004).

The fact that talking about death will always be a potentially upsetting, or at the very least uncomfortable subject of conversation, even within palliative care, sits in tension with the growing vogue for patients, and sometimes carers, to actively participate in decision-making about end of life care, such as by stating their PPD. This is also in tension with the overall aims of palliative care, which, throughout its history, has modelled an active rather than passive approach to the care of dying people, including finding new and imaginative ways for patients to be involved in their own care, up to the very end of life (Clark, 2002).

Notwithstanding the tension and difficulties of talking about such an emotive subject, my GT resonates with the developing societal trend of talking openly about death. In particular, my GT sees the expression of the patient voice regarding their PPD as one positive and specific way that society can hear about end of life issues which are pertinent to one group within that society, that is, hospice patients and their carers.

In addition to being part of a societal trend, hearing hospice patient voices on end of life care may change the landscape for individual people who will die in the future. As society begins to observe examples of how individuals currently negotiate this, arguably,

uncharted terrain, possible models of successful practice are being created and becoming reference points for future approaches to PPD.

New models of successful practice regarding end of life preferences are required at this time in UK society, because there is currently no agreed agenda, or norm, for cultural practices associated with dying. Walter (2003) argues that in former times, in the West, there was an agreed community script for dying, according to which, when death approached, the dying person's task was to send for the local Christian priest to visit them at their home to perform the last rites, after which they died within their local community context. Nowadays, in multi-cultural, increasingly secular UK society, it is much less easy to discern an agreed community script for dying and indeed living. Individual scripts, based on the exercise of personal choice and autonomy, are much more in evidence. An illustration of this is how contemporary healthcare chaplaincy operates. Instead of involving the practice of one set of religious rites, healthcare chaplaincy offers a space in which people are encouraged to explore and find their own spirituality, which may involve engagement with a particular religious faith or a mix of several religions, or no religion at all (Cobb, 2003).

Palliative care highly values and promotes personal autonomy and encourages individuals to make their own choices and therefore write their own individual scripts for dying and living. Within this understanding, a successful model of practice, that is, a good death, would be one in which the patient had made their own choices about their last days and months and in which these choices had been heard and acted upon. Conversely, a bad death would be one whereby a person exercised no autonomy and their wishes were unknown (Walter, 2003).



This view of a good death has, however, been criticised as one which is idealistic and not typical of current practice. Part of the reason for this may be that palliative care has many goals in addition to helping patients to face and plan for their own death. Recent years have seen the emergence of specialist palliative care, with an increasing number of medical treatments becoming commonplace and the encouragement of patients to access specialist palliative care at a point in their illness trajectory which may be further away from end of life than a previous palliative patient generation. Therefore, whilst palliative care has been very successful in assisting terminally ill people to live well to the very end of their lives, it is less certain that it has had the same measure of success in assisting people to confront and plan for the reality of their own death (McNamara, 2001). In support of this, the audit work undertaken at the hospice before the commencement of this grounded theory study indicated that only 28/150 (19%) of patients had documented their PPD and that 122/150 (81%) of patients did not have their PPD documented. Additionally, the hospice user group *The Patients' Forum* were reticent about using the word 'death' on the study invitation letter, as this was considered too blunt a way for hospice patients to confront their destiny.

Similarly, although seriously ill patients consistently state that having time to prepare for life's end is very important (Heyland, 2009), in practice, detailed plans for end of life are not always in place before patients die. One reason for this is that doctors sometimes avoid commencing end of life conversations until a time-framed prognosis is certain. This can limit opportunities for adequate information gathering and time to prepare for death. For example, at the stage when the time-framed prognosis is made, the patient may be too ill to deal with matters such as leave-taking within complex and sometimes geographically scattered families, or to complete unfinished business such as will-making or the sale of property.

It would seem then, that we are at a point in history when hospice patients are negotiating talking about end of life matters, without an agreed script, and according to individual circumstances and beliefs. Yet the way forward is far from clear: the acceptability of talking about end of life matters and the acceptability of particular procedures for achieving this are neither universally agreed nor embraced to the full. My GT, 'Enabling The Patient Voice to be Heard', presents the phenomenon of PPD as one helpful mechanism to assist in moving forward with end of life planning and it impacts the individual script notion by highlighting the importance of hearing the patient voice in order to allow the facilitation of individual actions.

It has long been observed that the cultural landscape of Western society has been substantially shaped by rationalism and science (Russell, 1946). Within healthcare this is realised in the strong need for control of health issues including death (The et al., 2000). In the West, ill-health and the eventual demise of individuals is largely approached as a problem to be managed by medical science. Thus a terminal prognosis is actively managed, whereby the focus is firmly kept on short term, science- based goals, such as the next medical appointment or the next treatment session. Hence longer term goals, including the inevitable path towards death, which may be more emotionally charged, fade into the background or are avoided. Thus, in response to the dominant scientific paradigm, all those involved in the care of terminally ill people, that is, patients, carers, healthcare professionals and indeed society at large, may, to some extent, avoid thinking and talking about the psycho-social aspects of death. Instead, they respond to the challenge of death by framing it as a medical issue.

My GT, 'Enabling The Patient Voice to be Heard' on end of life matters, challenges this cultural norm. Building on work which evidences the growing desire amongst patients to talk about and plan for end of life care (Shah et al., 2006; Aoun and Skett, 2013; Jones et al., 2011), my GT purports that, through confronting death by engagement with PPD, there can be positive consideration of end of life matters which are not exclusively focussed on short term medical goals.

Therefore, engagement with PPD by hospice patients could result in positive non-medical outcomes such as the setting of and achievement of personal goals. This would also allow time for responses from family, friends and healthcare professionals which could contribute positively to the achievement of the PPD and other goals, such as whom the patient spends time with during their last days and weeks of life. Facing the reality of a terminal prognosis by hearing the patient voice on end of life wishes could offset the possibility of reported regrets about such matters. For example, The et al. (2000) reported a case of a distressed son, who, having not been made aware of how close to death his father was, had gone on holiday and missed sharing his father's last weeks of life. Hearing the patient voice, then, at least allows for informed choices to be made by those for whom end of life is an immediate and pressing issue, that is, the patient and their family and friends.

Interestingly, however, an approach to end of life care which focusses on medical goals may not be entirely at odds with my GT. Traditionally, palliative care has embraced a model of care which is holistic, encompassing psychological, spiritual and social care, in addition to the treatment of medical symptoms. Clark (2002), however has noted an increasing medicalisation within palliative care, whereby suffering has come to be seen as a problem to be solved medically, with palliative care practitioners becoming

'symptomologists'. Whilst this higher deployment of technical expertise may result in better control of physical suffering, it marks a departure from the traditional 'low-tech, high-touch' approach to palliative care (Koshy, 2009).

However, such a problem-solving approach could interact positively with the notion of 'Enabling The Patient Voice to be Heard'. If the opportunity to explore the PPD were viewed as a problem to be solved, similar to the way in which medical symptoms are resolved, then it could become more likely that conversations around end of life care would be incorporated into routine practice, thus making it more probable that the patient voice would be heard.

Although my study was based in a hospice setting, the GT, 'Enabling The Patient Voice to be Heard' is relevant to many healthcare service providers because people die in various settings. For example, many people receive end of life care in acute hospitals; some die in nursing homes; those who wish to die at home may need support from community services such as district nurses, GPs and social care agencies. Additionally, some patients move between service providers during the terminal phase, for instance from the acute hospital to the hospice, or from home to acute hospital.

Moreover, recent years have seen an increasing trend for end of life planning opportunities to occur in clinical specialties and settings other than palliative care, such as in the Intensive Care Unit of acute hospitals, within Chronic Obstructive Pulmonary Disease (COPD) services, Kidney Dialysis clinics, General Medical and Elderly Care wards and Senior Citizen Centres (Heyman and Gutheil, 2005). The British Heart Foundation and Marie Curie, for example, currently run a pilot scheme in Glasgow amongst patients with heart failure, who have been identified as nearing the end of life (Marie Curie, 2011).

This scheme facilitates conversations about where and how patients want to be cared for at end of life and was set up in response to the view that end of life care for non-cancer patients could be greatly improved by greater knowledge of patient needs and wants at the end of life (Parliamentary and Health Service Ombudsman, 2015). Additionally, some commentators have suggested that the future direction of travel for hospice care is towards the care of an ageing population in general, rather than caring for, in the main, those with cancer and other serious illnesses, as the UK witnesses a demographic shift of palliative care into the care of older patients with complex needs (Hughes, 2015). This widening of the pool of those who will engage in end of life planning has, in part, been aided by the emergence of new tools which assist with talking about end of life care.

Advance Care Planning (ACP) is now established as part of the Gold Standards Framework (GSF) which aims to improve the quality of care for all people nearing the end of their life in line with their preferences. This includes living and dying well in the place and manner of their choosing (NHS, 2016). ACP includes the clarification of legal matters such as establishing the power of attorney for someone to act as the patient's proxy should they become too ill to speak for themselves; the opportunity to record advance decisions to refuse medical treatments (ADRT) and whether the person does not want to be resuscitated (DNACPR) or wishes to be allowed to die naturally (AND). Additionally, ACP provides the opportunity for patients to record their preferences about where they would like to be cared for at the end of their life in an Advance Statement of Preferences (AS). ACP is not a universally used set of pro-formas: there are a number of documents and tools currently in existence, including several locally developed tools, for example the Supportive Care Plan (SCP) developed by the hospice in this study (Thompson-Hill et al., 2009). Additionally, end of life wishes are sometimes recorded in patient's medical notes (Walczak et al., 2016).

Such a widening of participation in end of life planning across various healthcare settings and populations resonates with my GT's positive view that engaging with end of life planning enables the patient voice to be heard. This in turn, increases the possibility of patient's wishes being acted upon. Moreover, end of life discussions can assume a deep significance, for some people, as this affords the opportunity to draw close to a person's sense of meaning and values, of how they make sense of the world. Consideration of such issues can have the potential to enhance people's inner life, sense of optimism, autonomy, control and hope and thus improve their quality of life (NHS, 2016).

However, in reality, many conversations on the topic of end of life occur during an acute hospital admission when there has been a serious deterioration in the condition of the patient, that is, when they are approaching the terminal phase of their illness. At this point along the illness trajectory, the patient may be too ill to take an active part in a discussion about their end of life preferences and wishes, thus limiting the extent to which the patient voice is heard, as end of life conversations at this stage are sometimes too late, or of poor quality. In a study amongst patients with advanced, incurable cancer it was found that most end of life discussions took place one month before death and more than 50% of conversations took place in the acute hospital and not with an oncologist or palliative care specialist, but with the on-call team (Mack, 2012).

Other concerns include the accessibility of patients' recorded preferences. Fine et al., (2010) found that even when end of life wishes had been documented using an ACP, such preferences were often not recognised or acted upon by hospital staff as the patient's wishes were not communicated to the admitting team. In a similar vein, in a study amongst people who had less than six months to live, as few as 14% of doctors knew

patients' preferences regarding pain management or place of death (Desharnais, 2007). This low level of knowledge about patient wishes regarding end of life care amongst the very healthcare professionals who are administering medical and nursing care to patients at the end of their lives, demonstrates the antithesis of my GT. If the patient's voice on end of life care preferences is not heard, their voice will have zero impact on the end of life care they experience.

A further aspect of end of life care which is relevant to the actual care which people receive in comparison with their plans, concerns the co-ordination of out of hours services. Despite the fact that the 2015 Quality of Death Index (The Economist Intelligence Unit, 2015), ranked the UK as the best place to die, out of 80 countries, a staggering 92% of UK areas lack appropriate co-ordinated out of hours palliative care support services (Hughes, 2015). The report highlights examples of poor communication with patients and families and inadequate generalist and specialist out of hours services and calls for an improvement (The Economist Intelligence Unit, 2015). My GT supports the report's demand for progress in this area by underlining the importance of the patient voice being heard, in order for the planning of services to allow, at least some, matching of patients' true wishes with services provided.

The fact that end of life planning can involve several healthcare service providers adds weight to the argument that 'Enabling The Patient Voice to be Heard' concerns more than matters of individual doctor-patient communication. It touches on finding effective means of sharing information across service providers in order to make patients' wishes and preferences a reality. It may also perhaps require a greater commitment by all those involved in the care of dying people, including patients themselves and their close carers, to discuss and record their wishes regarding end of life care (Desharnais, 2007).

That is not to say that effective communication between patients, carers and healthcare professionals is irrelevant. Acknowledging the fact that communication about end of life can be a challenge for all stakeholders (Walczak, 2014), it is nevertheless problematic that sub-optimal communication between patients and their doctors regarding end of life care can lead to poor decision-making and outcomes at end of life (Walczak (2013).

A number of studies using directly observed physician-patient interactions in end of life care have shown that, in general, physicians tend to focus on medical and technical issues and avoid topics that cover quality of life and emotional issues (Tulsky et al., 1998; Roter et al., 2000; Detmar et al., 2002; McDonagh et al., 2004; Liden et al., 2010).

Timmermans et al. (2005) showed that psychosocial topics are raised ten times more by patients and families than by doctors. The effect of the tendency of physicians to concentrate on procedural and treatment matters is amplified when the domination of such conversations by physicians is taken into account. Several studies showed that 60-70% of the discursive space is occupied by the physician voice (Tulsky et al., 1998; Roter et al., 2000; McDonagh et al., 2004; Timmermans et al., 2005; Ohlen et al., 2008). The literature, then, paints a picture wherein many physicians see their role as information and recommendation giver, rather than listener of patients' views and concerns regarding death and dying (Detmar, 2002; Clayton, Butow and Tattersall, 2007).

This is intriguing as there are now many communication skills training opportunities for physicians and other palliative healthcare professionals, and for some palliative care professionals, such training is now mandatory. Perhaps there is a need to evaluate whether discussions encouraged by current training programmes are well focussed in the area of end of life care conversations (Desharnais, 2007). My GT draws attention to the importance of the patient voice being heard and therefore supports the development of



an approach to healthcare professional communication skills training which emphasises the consideration of the healthcare professional roles and responsibilities in end of life planning (Fine et al., 2010) and one which prioritises the listener role over that of information giver.

The patient and carer roles within communication at end of life is now featuring as an important part of the end of life care landscape. Indeed, delivering care consistent with patient and family goals and values and effective communication between physicians and patients and carers is the foundation of good end of life care (Fine, 2010). In particular, tools such as patient held records are becoming more common (Cornbleet et al., 2002) and interventions to inform patients about end of life options and to assist them to articulate their wishes regarding end of life are also being developed. For example, Grimaldo (2001) reported on an information session about Advance Care Planning (ACP) for elderly patients undergoing surgery; Jones et al. (2011), reported a highly structured one-to-one Advance Care Planning intervention for cancer patients after first –line chemotherapy, and Heyman and Gutheil (2010) reported on an intervention to assist elderly nursing home residents to express their wishes regarding end of life. Another interesting contemporary initiative is the Death Café movement (Underwood, 2011), which facilitates social events where people talk about death. Attendance is open to all. Although not specifically aimed at end of life care planning, Death Café is an illustration of increasing opportunities in society for lay people, including patients and carers of terminally ill people, to exercise active involvement in talking about death.

Similarly the carer role is increasingly recognised in the literature, with new initiatives designed to encourage carer participation in end of life planning becoming more evident. For example, Chih et al. (2013) reported on a web-based end-of-life and communication

education; Lautrette et al., (2007) reported on a structured end-of-life focussed family conference with written bereavement information and Fukui et al. (2013) reported on structured family meetings directed by evidence-based guidelines.

It would seem then that there is a gradual development of the role of the patient and carer in end of life planning, which may herald a model which is more based on partnership between users and professionals. To date, the evidence base for the establishment of such a model is small: demonstration of patient and carer involvement is currently patchy and long term outcomes of such action are unknown. Despite carers shouldering a substantial burden of the actual end of life care given to patients, interventions encouraging their involvement in end of life planning remain few. The picture with patients is a little better, in that interventions on end of life communication education and advance care planning appear to have a positive impact on outcomes. This includes patients expressing significantly more positive attitudes to and comfort with end of life planning and a greater power of attorney completion, as well as lower hospital re-admission (Walczak, 2016). This nascent and budding sense of patient voices being heard through their engagement with various end of life planning mechanisms, is thoroughly in keeping with my GT 'Enabling The Patient Voice to be Heard'.

#### **10.4 Summary**

This chapter has considered how my GT, 'Enabling The Patient Voice to be Heard' impacts the landscape of end of life care. Various important aspects of current end of life care have been explored in relation to this, including societal attitudes to talking about death; current and developing models of practice at end of life and the ways in which this relates to end of life planning; the role of medicine in end of life planning and care; the necessity to consider end of life in relation to the wide spectrum of health service provision; the role

of recent initiatives in end of life planning such as the Advance Care Planning Portfolio (ACP); the quality and content of communications between healthcare professionals and patients in end of life planning and the roles and responsibilities of healthcare professional, patients and carers in end of life planning.

Chapter 11 will present a reflexive account of the research process and the limitations of the study.

## **Chapter Eleven      A Reflexive Account of the Research Process and Limitations of the Study**

### **11.1 Introduction**

This chapter outlines how I adopted a reflexive stance to this study. My particular understanding and use of reflexivity within this study is presented. Reflections on the process of conducting the research are offered and the limitations of the study are presented and discussed.

### **11.2 Taking a Reflexive Stance**

Reflexivity is often regarded as a useful tool for ensuring the standard of qualitative research (Parahoo, 2006). This is because of the way qualitative researchers position themselves in their research, that is they do not regard themselves as objective observers of social situations (Colaizzi, 1978), but see themselves as participants in dynamic relationship with the research being undertaken (Ryan and Golden, 2006). If researchers do not have an objective position with respect to their research, questions regarding the validity of the research arise. The adoption of a reflexive stance is seen as a way of enhancing confidence in qualitative research and establishing the researcher's credibility (Patton, 1999; 2002,); as a necessary element of quality (Holloway and Freshwater, 2007) and as a means of making the researcher's position transparent (De Souza, 2004).

In recognition of the potential impact of personal dynamics on the research setting, reflexivity has been widely used in relation to qualitative data collection methods, particularly with regard to interviews. In qualitative interviews, the researcher, a human being, is the data collecting instrument rather than an inanimate object such as a blood pressure monitor or a questionnaire. Human beings interact with each other and such interaction may influence the data gathered, thus calling into question the research's

scientific value in terms of validity. Gabrielle, Jackson and Mannix (2008), recommend that a qualitative research report should contain information regarding any personal and professional factors that may have affected data collection, analysis and interpretation whether negatively or positively. Reflexivity describes the relationship between the researcher and the object of the research (Brannick and Coghlan, 2007).

The aim of aiding rigour is achieved due to reflexivity's capacity to provide transparent information about the positionality and personal values of the researcher that could affect data collection and analysis, (Walker, Read and Priest, 2013a). Hence, taking a reflexive stance as an integral part of the research process is deemed to be best practice.

Therefore, I decided to adopt a reflexive stance during this qualitative study.

From the outset of this research study it was agreed by the supervisory team that taking a reflexive approach by keeping a reflective research diary would benefit me, as novice researcher, in a number of ways. It would assist in ensuring that the eventual theory generated would be grounded in the data and thus demonstrate a degree of trustworthiness (Whittemoor, 2001). Furthermore it was firmly understood that a PhD is about more than getting the research done; it is also about research training to equip the researcher with a set of ultimately transferable skills. It was felt that recording such professional change and growth within the pages of the research diary would accord well with the concept of promoting an understanding of self in context (Freshwater and Rolfe, 2001).

A further dimension of this research study which demanded a reflexive stance was my former status as a member of staff at the hospice where the research was situated. This created the potential for insider research concerns to influence the way the study was

conducted (Arber, 2006). Therefore, anticipating concerns around insider research, the supervisory team decided against techniques such as bracketing (Scott et al., 2008) and suggested instead that I make explicit notes of my own responses to any encounters which touched upon insider research (Martin et al., 2007).

The desirability of taking a reflexive stance was all the more important because this research was a constructivist grounded theory study. This methodology explicitly demands a reflexive stance which informs the readers how the researcher conducts his or her research, relates to the research participants and represents them in reports (Charmaz, 2006). The way in which reflexivity contributed to rigour in this study is rather subtle. In addition to being a guarantee of the trustworthiness of the research (Bulpitt and Martin, 2010) and a safeguard against investigator bias as suggested by Lincoln and Guba (1985), reflexivity added extra texture to this research by presenting a complete view of the research process. My approach was akin to what Gadamer (1975) meant by 'signposting the reader' to what occurred in the research and as a means of actively and systematically developing insight into my work as a researcher in order to guide research decisions and actions (Birks and Mills, 2011). The strategy I adopted for this was keeping a reflective research diary.

The research diary was qualitatively differentiated from field notes, which may be described as a place in which to record annotations about research activities from an outsider perspective. It is also different from memo-writing which may be described as the notation of potential ideas for theory generation. Rather, in the reflective research diary I recorded observations, thoughts, feelings and reactions which arose during the course of conducting the research. At the data collection stages, the diary was completed as soon as possible at the end of each day's field work in order to capture fresh

observations about interactions with research participants and data, in addition to thoughts and feelings which had arisen during the course of the day. This is consistent with Finlay's (2002) notion of reflexivity as a process whereby researchers engage in explicit, self-aware analysis of their own role. During the data analysis stages, I wrote in the diary whenever the need arose to reflect on the research process, emerging ideas, or my thoughts and feelings. I considered the diary **my** input into the research and part of theoretical sensitivity.

Theoretical sensitivity was originally described by Glaser and Strauss as concerning the researcher's personal and temperamental bent and their ability to have theoretical insights into their area of research (Glaser and Strauss, 1967). Arising, initially from the researcher's professional and experiential history, theoretical sensitivity is the ability to recognise and extract from the data, those elements which have relevance for the emerging theory (Birks and Mills, 2011). Charmaz includes theoretical playfulness, whimsy, wonder and especially the ability to remain open to theoretical possibilities as integral parts of theoretical sensitivity (Charmaz, 2006).

The research diary, then, aided my theoretical sensitivity in allowing ideas for theory building to be noted and tested. It was referred to during the process of theory generation, for example during the coding and categorising stages of analysis. This proved to be a great aid in conceptualising the raw data as diary entries captured something of the essence or mood of a particular encounter such as an interview or focus group and in this way it brought life to a dry transcript. Taking diary observations into account alongside transcripts and memos often served as a useful technique in formulating abstract concepts from discrete chunks of data, in addition to its usefulness in providing a record and comment on the research process.

### **11.3 Reflections**

The reflective research diary provided a place for contemplation on the process of conducting the research and provided a place in which to record and reflect on the various contingencies which occurred.

#### **11.3.1 Being a Guest in a Working Institution**

The diary recorded issues around the mechanics of conducting research in an institution in which members of staff were going about their daily work. A balance between being a courteous guest in a host institution that had never before allowed research to be conducted, and being persistent in gathering the required data in a timely and efficient manner had to be found. I was frustrated when the staff forgot I was coming in to the hospice to conduct patient interviews on certain days and had, therefore, not made a room available for me. This meant that that on these occasions, there were delays in getting starting. I felt this was not the best way to conduct an interview with a vulnerable person and that this made me look inefficient.

In the diary I reflected that these problems were a feature of the potential disconnect between theoretical preparation for fieldwork and the realities of accessing data on the ground. I noted that I'd seen a book entitled *Real World Research* (Robson 2002), and wondered whether it should have been called *What Your Supervisor Never Told You Before You Started Your Fieldwork*. Robson (2002) would probably have argued that sharing information about difficulties, hitches and frustrations with other novice researchers could be an empowering action because the diary also records how difficulties in the fieldwork were eventually overcome and the research was completed successfully.



I reflected in the diary on the actions required to ensure that I had communicated effectively with staff about the time and date of subsequent interviews. After this reflection, I came to see this issue as less problematic and more instructive of how pragmatic research decisions are valid, integral parts of research and how reflexivity adds necessary insight into the complex dynamics that exist in quantitative research (Ryan and Golden, 2006).

### **11.3.2 Potential Insider Researcher Issues**

Issues around professional boundaries and integrity were detailed in the diary. I wondered whether my status as former chaplain would affect the research. My trepidation at returning to the hospice was noted on the first page of the research diary:

*First day: some nerves about being back where I was working 15 months ago.*

*How will the staff react? What will I feel like being in the building and meeting ex-colleagues and new staff?*

I noted that being an ex-colleague made for some interesting interpersonal encounters, some of which were helpful to the research, for example in interest shown in the study by staff. For example at the end of the first focus groups, one member of staff insisted on taking me to her office to tell me, in some detail, about the very recent innovation of *The Supportive Care Plan (SCP)*, which had been mentioned in the focus group. This document, hitherto unknown to me, had recently been introduced at the hospice and was not yet published or widely available outside the hospice. It was particularly relevant to my study because it included the opportunity for patients to have conversations about end of life wishes. I noted that:

*This document is not yet even on the computer system, yet alone in any research database. Without good relationships and conversations with staff, how could a researcher find this information? Then again, I am a novice. Maybe a more experienced researcher would have asked if there was any further documentation to be found.*

In the diary I revealed how I felt momentarily dismayed at the discovery of The *SCP* because it seemed that that the hospice was already addressing PPD and that my research was unnecessary. The diary entry concluded, however, with an exhortation to positive thinking: the information formed part of the research and would serve to inform the next staff focus group and the patient and carer interviews. I did, however, wonder whether this collaboration with staff was permissible.

*Staff are helping me ... What would the LREC say? Is this a conflict of interest or is this merely part of being embedded within this context?*

Mruck and Mey (2007), argued that to be involved personally in a research topic is not necessarily a problem and may even have advantages: personal experience can lead to insights and perspectives that may remain inaccessible to outsiders.

Some encounters with staff were less helpful and delayed the process of data collection. For example some still viewed me as a chaplain and not as a researcher. I recorded that several members of staff who attended the focus groups or who encountered me at the hospice on days when I was conducting patient and carer interviews, felt free to discuss their troubles with me and, in some cases, felt able to ask for advice: 'Have you got a minute, Rev?' and 'Oh great, I could do with a talk with you', are cited as typical examples

in the diary. These types of encounter were perhaps inevitable and had to be negotiated sensitively and with integrity.

Many insider researchers have grappled with this issue. Arber (2006) conducted research in a hospice, where she was a researcher and a practitioner, and found that keeping a reflexive journal helped to manage the boundary between closeness to the research topic and the distance required to carry out the research in a professional manner. In my case, my 'insider conversations' had no adverse effects on the progress of the research, but prompted me to ponder on my status as near insider.

On a more personal level, the diary noted that data collection had an emotional effect on me when I encountered two interview participants who were patients I'd formerly known as chaplain. In order to minimise any effect this may have had on data collection, at the start of the interview with these participants, I made it clear that we were not meeting as chaplain and patient, but as researcher and participant. Moreover, the topics covered in the interview were clearly about the research study and not topics that would be typical of a patient accessing spiritual care. However, it is true to say that both of these participants responded to the interview situation with ease, as the rapport from our former relationship was still evident, in that we, clearly, enjoyed talking to each other again. In the diary I recorded that these encounters left me with a sense of the poignancy of research about patients I had cared for and of emotional labour expended (James 1992, Smith and Gray 2001). Etherington (2004) commended the kind of critical subjectivity that keeping a research diary allows, especially in health research where researchers have generally been socialised into professional ways of thinking that can affect how they approach their research data.

### **11.3.3 Reflecting on the Analysis Process**

Within the diary I logged an emerging sense that ideas about analysis started to form during the various stages of data collection. I sensed that, as I was learning to manipulate my chosen research methodology, I was experiencing for myself the fact that the relationship between data collection and analysis is not necessarily linear, or constitutive of one-way traffic. At an early stage of analysis, I noticed, with satisfaction, that I was definitely using an inductive approach to data collection and analysis. An entry in the research diary asked the following question: 'Is this all a consequence of following the data as a grounded theorist?' It felt appropriate that the research was beginning to follow the data. Of course, this was entirely in keeping with grounded theory methodology, which lends itself to the exploration of emerging research ideas that may surface at any stage in the research, as the constant comparison method encourages dynamic interaction between data collection and analysis (Strauss and Corbin, 1990). However, the diary captured my novice researcher's sense of excitement as theoretical ideas began to form, as I engaged in active learning (Bonwell & Eison, 1991), through 'doing the methodology'.

In addition to my reflections on how I was engaging with the methodology, the diary provided a useful place in which to think 'out loud' about decisions regarding data analysis, especially when the way forward seemed unclear. For example, I reflected on the fact that I was unsure how to manage the many line-by-line codes which were generated by the seemingly extraneous, irrelevant and somewhat banal biographical details which were recorded at the beginning of an interview. The matter of whether they should be omitted as irrelevant to the growing analysis or included as legitimate facets of the data had to be faced. If the biographical codes were omitted, this begged the

question whether this analysis would present a true and complete picture of the participants' situation. This extract from the diary encapsulated the problem:

*And what about all that stuff early on about how they live their lives now with their illness, about how having a cleaning lady means a couple can spend more time together and how one gentleman loved going to the hospice as it meant "I can see me mates". . . Just ditching that stuff would feel like cutting a scene from a film – won't that affect the telling of the story?*

In the diary I noted that about 50 codes per transcript referred to biographical details of participants' lives. I questioned how this had come about and whether I had been mistaken in allowing this to happen. As a means of allaying my concerns about this I wrote about why I had planned my interview schedule to include early questions about the participant's everyday life. I reminded myself that the early questions about participant's circumstances were designed to put the participant at their ease in the initial moments to enable them to relax into the process of talking. I had envisaged that questions about the participant's everyday life, would perhaps begin to build a measure of trust between myself as interviewer and the participant, so that within this quasi-conversational context the participant would feel comfortable telling their story and revealing something of themselves in the telling.

I had anticipated the requirement of such a trust-building approach due to the sensitive nature of the research topic, that is, the preferred place of death of these research participants, all of whom were living with an ever approaching terminal prognosis. Viewed from this perspective, it seemed entirely logical that the early part of the interview which involved asking non-threatening questions such as about the patient's date of birth,

where they lived, their interests and hobbies, would result in a fair amount of peripheral material, sometimes greatly detailed, being gathered in the transcript.

Reflecting in this way reminded me that the aim of the interview was to gain the participants' perspectives: their thoughts, feelings, opinions and experiences around the research topic of PPD should come tumbling out unhindered by intrusive and possibly stultifying interjections by me, a potentially clumsy interviewer. The object of the exercise was to elicit the experiences of the research participants and not merely to gain answers to the interview schedule questions. Hence, I learned that allowing the participants to cover all the ground they wanted in their accounts, whether strictly relevant, tangential or frankly rambling and way off topic was integral to the qualitative research task and represented the participant exercising a degree of control over the interview (Holloway and Wheeler, 2010). I noted that this mass of data felt like some sort of ore which I could mine for precious elements of theory.

From subsequent reading on this topic, I then learned that, whilst Holloway and Wheeler (2010) have referred to the amassing of such material as "the dross rate", meaning material not directly related to the study and therefore of no particular use to the researcher, other writers take a different view. Stone-Mediatore (2003) considers it to be very important that researchers do not excise people's stories in the way they tell them themselves and that the seemingly extraneous biographical material could be seen as an alternative form of knowledge about the participants' social world. I wrote about how I came to the view that in the course of my interviews, I had no wish to silence the participants in any way; rather I had a desire to promote what Mishler (2005) calls *the voice of the lifeworld*. For me, the task then, was to remain attentive to the voice of the lifeworld of each participant whilst further conceptualising the data.

Moreover, by remembering and reflecting on the purpose of the interviews, that is to ascertain the participants' views, this prompted a degree of theoretical thinking. If giving an authentic portrayal of participants' lifeworld was important, then the eventual grounded theory must also connect with a faithful rendering of processes impinging on the lives of these particular participants. In the diary I stated my growing understanding that the theory must be constructed from these building blocks of data if it were to be truly grounded theory. This had implications for the fact that this is was constructivist grounded theory: the philosophical underpinnings of which state that social reality is constructed by those experiencing it. Therefore, how participants portrayed themselves in the data would be indicative of how they constructed their social reality. If my theory were to be congruent with a constructivist view, the lifeworld of participants should be a relevant part of data to be taken up in the analysis. (Watson and Girard, 2004).

These reflections charted, not only the ongoing progress of the research, but also the ongoing progress of myself as researcher.

#### **11.3.4 An Unexpected Ethical Issue in Focus Group One**

One unexpected and poignant facet of the first focus group, noted in the diary, was, that one member of staff who chose to participate, had been recently diagnosed with cancer and was at the time of the focus group undergoing a course of chemotherapy. Her current status as a cancer patient was evident to all by her headdress which was covering a, now bald, head which served as a somewhat arrestingly visual reminder of the real world context of this research. Other members of the group seemed to be aware of this person's current medical status and some made jovial, yet caring comments about this after the focus group had ended.

In the diary I recorded my surprise to this person's answer to my question about whether she was sure she wanted to take part in the focus group in view of her current circumstances. She was emphatic in her 'Yes' and characterised her desire to take part 'now more than ever' as being part of the professional drive to deliver the best quality patient services. I also noted that I felt a bit upset and shocked at this person's appearance because 'cancer happens to patients not colleagues' and that, in my view, the cancer experience shouldn't be part of Staff Focus Groups but, rather, the Patient Interviews.

In this instance, the diary afforded the opportunity for personal reflection. This highlighted researcher vulnerability in conducting research into end of life care and the need to have time and space in which to process upsetting information. This course of action was clearly beneficial as the diary entry ended with the assertion that this was 'an in yer face reminder of why I am doing this research' and as such acted as a spur to continue with this important work.

### **11.3.5 A Patient Participant Who Was Too Ill for Interview**

I had failed to make contact with two patients through the normal recruitment process. I sent them a follow up letter, saying I'd now conducted enough interviews but if they were still keen to have their views included in the research, I would gladly arrange an interview to take their views. I never heard from one of these recruits, but the diary extract vividly recalled an arresting encounter with the remaining recruit.

*Today, Veronica phoned to say she'd now been given about 4 weeks to live and so felt she would not be able to have an interview. She did however want to talk to me there and then for a few minutes on the phone to tell me about her end of life*



*care plans. Somewhat taken aback I listened as this lady promptly told me how she was hoping to go into the hospice for the end and that she's told staff this. She is confident that she will receive the care she will need in the hospice. Her 3 sons have each offered to take her into their home but she has declined this, mainly because she does not want her grandchildren to see her as she gets worse: she wants them to have happy memories of their granny when she stayed with them for weekends etc. when she was well and she wants to protect them from any unhappy memories that may ensue. She sees considering the family and their future as an important part of being a mum and a grandmother. In the meantime, she has agreed to have carers coming to the house to assist her until it is time to go into the hospice.*

*Veronica could not talk for very long today, due to breathing difficulties. I wished her well for her future, thanked her sincerely for taking part in the research in this manner and reminded her of my hope that the point of this was to ensure that future patients continue to get the very best of care and that her view as told to me today was part of this endeavour.*

I further wrote, with candour, my emotional response to this encounter; how I felt humbled that someone with 'such a lot on their plate just now' would take the time and trouble to help me with my PhD and how I felt moved just thinking about the fact that this lady is coming towards the end of her life. I reflected that when I was a practitioner in palliative care I took the emotional labour of facing death for granted; like most palliative care practitioners I just got on with the task in hand. Moreover, in that role I had access to professional systems to assist with issues of emotional labour, for example

informal peer support, clinical supervision and in my role as chaplain, prayer. I noted, however, that as a researcher, I was removed from constantly breathing the palliative care atmosphere and was now a somewhat isolated researcher and therefore felt the need to note the poignancy of the encounter in the pages of the research diary. I was keen to record the following: the positive receiving of her view (positive for both of us), my sadness at the thought of another human being's death and yet the lingering feeling that this had been an encounter that was not without hope for both of us. As I wrote in the diary:

*The hope business is something I felt often as a hospice chaplain and it's a bit hard to explain ..... there is something about human beings trusting each other and connecting with each other at a kind of deep and fundamental level – often unspoken – when faced with the ultimate reality death. It may be that the chaplain or other health care professional has been one of the few people who has been able to withstand the tide of emotion which is inevitably part of facing death: perhaps relatives and others just can't face talking about it and would rather try and jolly the patient along, tell them to keep fighting or that they'll soon be better or avoid the subject altogether and resort to talking about the weather or the latest episode of Coronation Street.*

*By contrast in the Health Care Professional, the patient finds someone with whom they can "share the darkness" (Cassidy 2002), face reality and know that in some way this is OK. The HCP may even become emotional with them, but they won't run away, they won't deny the reality of impending death, they won't try and offer solutions, they will simply "hold the encounter", accept it. Somehow this engenders a deep sense of trust and seems to give birth to hope.*

*Today's encounter felt like this. I remain humbled by it, grateful for it and inspired to get on with the PhD. If the patients care enough about the research to take action within the last weeks of their life, then I have a duty of care towards them to work hard at this research.*

In addition to recording my emotional response, I used the diary to reflect that this encounter had renewed my belief in the aims of the research: to positively influence palliative care. I wrote that patient and carer views have not been researched in this way before and perhaps my work really would impact service delivery. At the very least it gave a dying lady the positive experience of having her view listened to and valued and that has worth in itself. To be able to receive something from this dying woman felt like I'd also given her something. I asked the question: 'Is this the therapeutic value of taking part in qualitative research?'

In these ways the research diary provided space for personal reflection and perhaps a necessary safety valve for dealing with the emotions concomitant with working with end of life issues. Moreover, this reflective exercise had a positive impact on the progress of the research in that it renewed my commitment to the work.

### **11.3.6 A Disclosure of Thoughts of Suicide**

During the course of an interview, one patient participant in the study disclosed that she had thought about ending her own life, at some non-specified point in the future, rather than waiting for the end to come more naturally. She declined to talk about any detailed plans she might have as a means of establishing clearly that no one else should be implicated in what might be viewed as an assisted suicide and thus an illegal act.

Although I considered this a matter of sober import to this patient and, as such, one which demanded my full attention, I was not unduly distressed by the encounter.

Interestingly, this did not constitute a disclosure of something which I was ethically compelled to refer on to the appropriate named person at the hospice, as would have been the case for example if some kind of abuse had been disclosed. However, I noted that this caused some thoughtful consideration on my part. I used the diary to record my actions and deliberations and feelings on this matter.

Firstly, with regard to action taken: I decided to discuss this in confidence with the nurse in charge of this patient's care. This was easily achieved I had worked closely with this very experienced nurse over a number of years. She was quite clear that because no detailed plans had been disclosed, there were no legal implications to follow up. The nurse was also aware of this patient's views on the subject as the patient had, apparently, spoken openly about this with hospice staff on a number of occasions.

I reflected that I'd felt this was a serious matter and as such it warranted being discussed with hospice staff as this was part of my responsibility as a good guest within this host institution. Additionally, I wanted to react to this disclosure in a sensitive and responsible manner, ensuring this participant had access to relevant support regarding this matter. I noted how expressing care for this participant felt entirely appropriate.

I also noted reflections after discussing this incident with supervisors. It was interesting that both supervisors seemed to be somewhat shocked by this encounter: certainly much more so than I had been. They stressed the importance of referring this to the hospice and the necessity for careful documentation of this encounter. I wondered why I had not

been disquieted by this encounter in the way that my supervisors seemed to be. I reflected that this was probably due in part to my many years' experience as a palliative care chaplain in which many patients had discussed with me their thoughts of suicide, particularly when first diagnosed with a terminal illness or at times of great physical, mental or spiritual difficulty. Several had even asked me to assist them in ending their lives.

I wondered whether I'd become inured to the discussion of such matters and whether habituation was good or bad in terms of this research study. I concluded that this was merely symptomatic of being well-versed in hospice culture and life. Furthermore I reasoned that, on balance, my experience would be of definite positive benefit to the research as this enabled me to get alongside participants with some measure of ease. What is more, being accustomed to interacting with hospice patients, carers and staff enhanced my ability to confidently yet sensitively probe subjects around PPD as they arose.

#### **11.4 Limitations of the Study**

All research has limitations and this study was no different in this aspect. The limitations encountered are now discussed.

The number of carers recruited to the study was small (two) and this was initially somewhat disappointing. It is difficult to envisage how this situation could have been greatly improved, but perhaps more attention could have been given to articulating that potential carer participant commitment required was minimal (one interview), and underlining the potential benefit of this research to palliative care practice. Moreover, the pragmatic decision to proceed with the two carers interviews was vindicated, in that, an

acceptable level of saturation was attained after the two carer interviews. Additionally, whilst there has been some research amongst carers regarding end of life care of palliative patients (Townsend et al., 1990; Thomas, Morris and Clark, 2004; DH, 2012), this has largely been conducted post bereavement. My research study, however, included views of carers before the death of their loved one and so made a valuable contribution to the knowledge base in this area. This supports the case for further research amongst carers with loved ones who are still living.

A second issue was that the recruitment of patient participants was subject to a certain amount of gatekeeping on behalf of the hospice. This occurred because the Day Hospice manager only approached patients whom she judged to be interested in and capable of conversing about PPD. This demonstrates the powerful position of gatekeepers (Walker and Read, 2011a) and the paternalistic and tokenistic potential of gatekeepers' actions (Miller and Bell, 2002).

Perhaps a more confident and robust conversation with hospice gatekeepers prior to commencement of the study would have been helpful. Such a conversation could have pointed to the value of supporting patient autonomy in deciding for themselves whether or not to participate in the study. In addition the potential benefits to the patients in taking part in the research in terms of self-esteem and the exercising of agency could have been more clearly outlined.

It must be remembered, however, that when this study was commenced the notion of PPD was relatively new to this hospice. This was significant because any examination of clinical practice is always a delicate matter, and perhaps institutional anxieties around research resulting in an unsympathetic portrayal of less than perfect practice are

heightened when the practice in question is in its infancy. Moreover, research of any kind had not been undertaken at the hospice before, so the staff were understandably cautious in their approach. It would be interesting to discover the hospice's current attitude to taking part in such research. It is hoped that by sharing and reflecting on this experience in the academic arena, this will aid such developments and improvements in practice (Bolton, 2001).

It was impossible to recruit patients on the in-patient unit. It was known that the hospice would not allow this due to the fact that these patients were considered too ill to take part in research; also because some in-patients would actually be dying, it was judged inappropriate to conduct research in such a sensitive clinical setting. This is in keeping with the literature which depicts difficulties in identifying, recruiting and retaining terminally ill patients into research (Steinhauser et al., 2006; Addington-Hall, 2002). However, the success of this study may advance the case for research amongst in-patients in the future. This study demonstrates both the need and value of research which captures the patient perspective. Moreover, the fact that patient participants did not suffer undue distress during the course of the study makes evident that sensitive research can be successfully carried out in an appropriately sympathetic manner.

As this study was qualitative, it was never envisaged that the results yielded would be generalizable to other contexts. Its value resides in the rich, in-depth, context-specific data and analysis it has generated. Factors such as social class and levels of deprivation experienced by participants did not feature highly in this study as the overriding concern was the participants' hospice experience regarding PPD. However, a further research could investigate whether demography is a significant factor in engaging with PPD.

This study was set in a large hospice within an urban location, on the edge of a substantial conurbation in the Midlands. Thus, this hospice serves the local demographic wherein the population experience their particular disease burden. This is in turn influenced by particular socio-economic factors associated with living in this particular social milieu, with its recognised high unemployment, low incomes, poor housing and low rates of educational achievement. It would be interesting to compare the results of this study with a similar study which could be undertaken in a hospice in a contrasting location. For example, it would be interesting to see whether a study in a rural setting whose local population experienced a different socio-economic background, replicated the issues raised by this study and whether different issues were identified in this different setting.

Another possible limitation of this study concerns the fact that it was conducted solely amongst hospice patients, carers and staff whereas many terminally ill people have no link with a hospice, but are cared for in acute hospitals, nursing homes and in the community. It would be interesting to see research on this population's experience of PPD.

### **11.5 Summary**

This chapter has demonstrated and illustrated the approach taken to reflexivity in this study. Through excerpts from the research diary and thoughtful comments on the use of the diary, a rounded picture of how this study was conducted and decisions made during its course has been given. This gives weight to the view that keeping a contemporaneous narrative account of research activities is a valid means of recording important decisions and can also help to make research decisions. This is in keeping with the constructivist grounded theory methodology of this study. Using a reflective diary in this sensitive



research project , demonstrates that reflexivity can be an important element in helping researchers, providing a way to create dialogues about the challenges and difficult experiences potentially encountered (Owens and Payne 1999).

In addition to chronicling the advancement of the research and perhaps more importantly, the use of reflexivity within this study has portrayed my development as a researcher. It charted my progress as I mastered the techniques and strategies required to successfully complete this study.

The limitations of this study have also been presented and discussed. Chapter Twelve will present conclusions.

## **Chapter Twelve Conclusions and Recommendations**

### **12.1 Introduction**

This chapter presents the conclusions arising from this study. The purpose of the study is re-visited and consideration is given as to whether the original aims were achieved. The unique contribution of this study is articulated and recommendations for further work are suggested.

### **12.2 The Purpose of the Study Re-visited**

This study was designed to explore the views of patients, carers and staff in one UK hospice around the topic of preferred place of death (PPD). The study was set against the backdrop of the UK Government's End of Life Care Strategy (EOLC, 2008) which states that patients' PPD should be identified, documented and reviewed. In seeking the views and experience of hospice patients, carers and staff on this topic, this study sought to explore the grass roots experience of those whom this strategy affected most keenly.

The context of the hospice in which this study was situated produced a particularly nuanced experience: at this hospice, the PPD was not routinely recorded. Available statistics revealed where patients of this hospice died but it was unknown if this was their place of choice. This study afforded the opportunity to investigate why this was so and what the issues around recording PPD might be from the perspectives of patients, carers and staff.

The aims of the study were to:

- To explore PPD from the perspectives of the research participants
- To generate theory about the participants' experience of PPD

It was envisaged that a detailed analysis of data gathered in the study would offer a better understanding of current practice in the ascertaining and recording of PPD from the perspectives of users and carers. The data gathered would be compared and contrasted by means of constructivist grounded theory methodology to generate a substantive grounded theory. Furthermore, it was hoped that the grounded theory would add to the knowledge base on end of life planning and make a useful contribution to discussions around future service provision.

This study successfully achieved its aims. The topic of PPD was successfully explored from the perspectives of the research participants via hospice staff focus groups and semi-structured interviews with hospice patients and carers. Arising from the data gathered, a substantive grounded theory, 'Enabling The Patient Voice to be Heard', was successfully generated.

### **12.3 The Unique Contribution of This Study**

This study adds its own unique contribution to the knowledge base on the hospice experience of PPD. It makes the compelling argument that hospice patients were willing and able to discuss end of life matters. It shows that carers actively wished to discuss end of life with their family member who was a hospice patient and that hospice staff perceived their role as assisting the patient voice on this matter. This is in contrast to earlier work which portrays a scenario wherein raising the topic of PPD was considered too upsetting for patients and carers to face and too difficult for healthcare professionals to attempt, (McCarthy and Addington-Hall, 1997; Elkington et al., 2001; Lynn et al., 2000). This study, however, showed that ascertaining, documenting and reviewing the PPD of hospice patients is both possible and in the best interests of all concerned as engaging with PPD is an important means of 'Enabling The Patient Voice to be Heard'.

This study considered whether the role of the patient in end of life planning is passive or active: it considered whether patients were docile consumers of end of life care or proactive co-creators of the care they received. The very act of taking up the opportunity to discuss one's end of life wishes is a dynamic act, challenging stereotypes of patients as powerless recipients, (Karazivan et al., 2015). A further facet of whether the patient role is active or passive in end of life planning which this study underscored concerned the use of "the silent voice". This study demonstrated that declining the opportunity to express one's PPD and thus using "the silent voice" was also a way of exercising agency. The silent voice is qualitatively different from not engaging with the topic of PPD due to never being asked whether one would like to express one's wishes. The silent voice is a positive means of 'Enabling The Patient Voice to be Heard' **if** it signifies the right to decline a conversation on PPD.

Consideration of the role of the carer was also part of this study's contribution to knowledge. The carer experience was an important factor in the generation of the grounded theory, 'Enabling The Patient Voice to be Heard', as carers in this study considered their interaction with PPD as an effective means of supporting their patient and a welcome aid in dealing with practicalities at the end of life. Attention to the role of the carer sets this study firmly within the current UK scene in which recent years have seen a growth in the awareness of the pivotal position that carers occupy in supporting people with a wide spectrum of medical conditions and disabilities. Carers' associations have proliferated, with some national organisations coming into being, such as Carers UK and Carers Direct. Moreover, carers' rights have recently been enshrined in law within the Care Act (DH, 2014), including the right to assessment of the need for support, and rights in the workplace. The significance of this increasing regard for carers as having a part to play in decision- making is an ongoing debate within the nationwide healthcare

economy. In presenting the views and role of the hospice carer regarding PPD, this study adds to that debate.

The view expressed in this study, that PPD conversations and planning can 'Enable the Patient Voice to be Heard', sits within the current UK government discourse around patients and carers as active agents within the healthcare system rather than passive consumers of healthcare. Within this discourse, there is some recognition that patient and carer goals are valid in and of themselves, and must be taken into account, and that families and carers are often *experts by experience* (Patient Voices, 2014). The Social Care Act (2014) advocates beginning with the assumption that the individual is best-placed to judge their own well-being and promotes the importance of considering the well-being of any friends or relatives who are involved in caring for the individual.

The role of the healthcare professional is also pertinent to this. In perceiving their role as that of assisting the patient to speak about PPD, the hospice staff in this study drew attention to the power dynamic which exists between the patient and the professionals who care for them. There is a great contrast between an approach in which healthcare professionals focus on problem solving and one in which they focus on assisting patients to articulate their own wishes and thus, ensure that their voices are heard. In this way, this study adds a sociological dimension to the current debate on choice in healthcare: in a context in which patients exercise choice, what are the implications for the role of the healthcare professional? (Karazivan et al., 2015).

At the outset of this research study, the venture seemed to be about exploring issues that had been identified around PPD: namely questions around whether the PPD of hospice patients was actually being ascertained and if not what could be done to facilitate a greater take up of this. This could have led to theorising which focussed on attempting to

find potential solutions to positively affect outcomes such as an improvement in PPD documentation. Moreover, the fact that one of the original observations leading to this research, that is, that many hospice patients were dying in the A&E Department of the local acute hospital, could have led this research towards finding practical ways to reduce the number of inappropriate admissions of terminally ill hospice patients at the local A&E.

As the research progressed, however, it soon became apparent that finding practical solutions to local healthcare economy problems were not the focus of this research. As soon as data began to be amassed, it was clear that participants' concerns were around the desire to express views on PPD and to name systems and attitudes which facilitated this or acted as barriers. Therefore, in true grounded theory tradition, following the data, this research became about the voices of a group of vulnerable people, that is, hospice patients (Payne, 2008). Hence the GT developed around questions concerning aspects of healthcare practice and societal norms which enable or disable the hearing of the patient voice on this matter. This constitutes a further distinctive addition to the debate around access to end of life care and how this relates to patient choice.

However, in considering what aspects of healthcare practice enable or disable the patient voice being heard, this study also considered some practical matters of day to day administration of end of life care provision. This study demonstrated that what is required to ensure the patient voice is heard at every stage of the illness trajectory, are co-ordinated service-wide systems which are robust enough to ensure that the patient voice is neither lost, inaccessible, nor considered NOT a priority. Hence this study contributes to the discussion on the development of healthcare systems which ensure the patient voice is heard by all relevant agencies.

Moreover, when viewed in the wider context of Western society at large in which talking about death and in particular talking about arrangements for end of life are not widely encouraged (Walter, 1991; Saunders, 2005), this desire of hospice patients to have their voices heard, which the research has uncovered, contains even greater significance. Instead of just having the narrow focus of a local hospice interacting with a local hospital, this research contributes to the societal debate around death as taboo. It also offers a comment on the potential of a vulnerable group to communicate a powerful and pertinent message to society. In these ways this research study contributes to with the current debate in UK society regarding discussing or denying death (Hickey and Quinn, 2012).

In summary this study:

- Demonstrates that hospice patients are willing and able to discuss end of life matters
- Challenges the stereotype of palliative patients as powerless recipients of care
- Portrays palliative patients as pro-active co-creators of the care they receive
- Introduces the notion that the use of the “silent voice” is a way of exercising agency regarding PPD
- Acknowledges the importance of the carer role in end of life care
- Demonstrates that carers view the consideration of PPD as a means of supporting their loved one and as an aid in facilitating end of life practicalities
- Draws attention to the role of the healthcare professional in end of life care and notes the influence of power dynamics in the patient-healthcare professional relationship
- Considers healthcare practice and societal norms which enable or disable the hearing of the patient voice on PPD

- Identifies the need for service-wide systems to ensure the patient voice is heard by all relevant agencies
- Contributes to the societal debate around death as a taboo subject
- Notes the potential of a vulnerable group to communicate an important message to society.

#### **12.4 Recommendations**

This study recommends that further sensitive research is carried out in sensitive settings in order to further knowledge in previously under-researched areas. Conducting such research may, of course, entail negotiating certain ethical barriers. Because the topic of this study was considered sensitive and the research population comprising hospice patients, carers and staff was also considered sensitive, it was necessary to negotiate several ethical hurdles before the study could begin. A reasonably large measure of concern was expressed by several bodies with an interest in protecting this vulnerable population from research which might be distressing. Therefore this research study was subject to a whole series of ethical reviews before permission to conduct it was granted. This comprised the university ethics procedure, the NHS ethics procedure and the hospice ethics procedures, plus the additional measure of consulting patients about the wording to be used in information sheets. The level of ethical scrutiny prior to commencement of the study, then, reflected the trepidations of several stakeholders and possible reasons for the dearth of research in this area (Walker and Read 2011).

The success of this study shows that such research can be successfully undertaken without detriment or harm to the participants and indeed serves to empower them. Arguably, the focus groups and interviews carried out in this study did have the potential to impact their lives in a negative manner. During the course of the study there was no



evidence to suggest that this was the case, however, as no participant became distressed or wished to withdraw. This study shows, then, that research which is sensitive and sympathetic to both research participants and topic being researched can be highly successful and add much needed new knowledge to an understudied area. It therefore makes a plea for conducting further sensitive research in sensitive settings.

The new knowledge generated by this study around the roles of patients, carers and staff also has implications for medical and nursing education around end of life. This study shows that patients want to discuss this issue but current literature shows that many healthcare professionals struggle to broach this subject with patients and in particular they struggle to approach this topic with direct questions and clear non-euphemistic language (Barclay and Maher, 2010; Thompson-Hill et al., 2009; Holdsworth and King 2009; Munday, Petrova and Dale, 2009; Murtagh and Thorns, 2009; Holdsworth and King, 2011). Education for healthcare professionals is required to support clinicians if they are to find effective ways to implement best practice in this regard.

This study challenges the perception that, because there has been a recent trend towards widespread availability and take up of communication skills training courses amongst palliative care practitioners, the exploration of PPD and other end of life care matters is also widespread amongst palliative patients (Desharnais, 2007). Future training could focus most particularly on raising the topic of PPD with clear non-euphemistic language within a healthcare culture which encourages end of life conversations as part of the normal routine (Fine, 2010). This would do much to create a positive impact on the future experience of patients regarding PPD and could influence the development of new models of service delivery.

My GT, 'Enabling The Patient Voice to be Heard', stands as a safeguard of good practice in end of life planning. The idea put forward in my GT could be used as a simple, helpful question to ask in the course of end of life care: Has the patient voice been heard? It could be very useful in practice as a most helpful and concise corrective or aide-memoire.

Moreover, this would not necessarily require more paperwork in terms of yet another separate document to be completed in addition to the routine medical notes and the already burgeoning ACP portfolio which may include a Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR); Allow Natural Death (AND); Lasting Power of Attorney (LPA) and Advance Decision to Refuse Treatments (ADRT). Rather, the principle of my GT could be actualised as a simple question on the end of an existing relevant form. The question would be: **has the patient voice about PPD been heard?** Perhaps more importantly my GT 'Enabling The Patient Voice to be Heard', could bring into the forefront of the mind of all those involved in EOL planning and caregiving, the artless yet crucial question of **whether the patient voice on this matter has been heard.**

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## Research participant invitation letter

16<sup>th</sup> January 2012

Dear Sir/Madam,

### **Invitation to take part in a research study**

I am Susan Walker, a research student at Keele University and I would like to invite you to take part in a research study which I am conducting as part of my PhD studies at Keele University.

Before you decide whether to participate or not you need to understand why the research is being done and what it would involve for you. The study is called *Preferred Place of Death – One UK Hospice Perspective* and it aims to find out what hospice patients and their carers think about choosing a place of care for death. By gathering such information it is hoped to develop future patient services. Taking part in this research study will not affect any care you receive from the Douglas Macmillan Hospice.

The enclosed information sheet tells you more about this study and what will happen if you take part. Please take time to read the information carefully and talk to others about the study if you wish.

Do feel free to contact me if there is anything that is not clear or if you would like more information. My contact details are on the reverse side of the information sheet. Take time to decide whether or not you wish to take part.

Thank you for your kind attention.

Yours sincerely

Susan Walker  
PhD Student  
Research Institute for Social Sciences



## Research Participant Information Sheet

16<sup>th</sup> January 2012

### *Preferred Place of Death – One UK Hospice Perspective.*

#### **Introduction**

This research is being carried out by Susan Walker who is a research student at Keele University. Susan is conducting this research study as part of her PhD studies.

#### **Aim of this study**

The purpose of this research study is to explore the views of hospice patients and their carers around preferred place of care for death. This involves exploring whether patients have considered choosing a place of care for their death and the factors which might influence such decisions. It is sometimes assumed that everyone would like to die at home, but we do not know if this is true for all people. By finding out what patients and their carers want, it is hoped to develop future patient services so that more people may be enabled to die in their place of choice.

#### **Why have you been asked to participate?**

You have been invited to take part because you are currently attending the Douglas Macmillan Day Hospice. Whether you choose to take part is completely up to you and you can withdraw at any time without giving a reason. If you decide not to take part in the research, this will not affect the service you receive from the Douglas Macmillan Hospice.

#### **What will happen during the course of the research?**

You will be invited to have an interview to discuss your views with Susan Walker. The interview should last between 30 – 60 minutes and can take place at the hospice or in your own home. The discussion will be guided by Susan Walker but you will be free to talk about anything relevant that is of concern to you. With your consent, the interview will be audio-taped.

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

Benefits for you include having the opportunity to talk about this sensitive issue and risks include the possibility of exposing deep emotions, which may be difficult for some people. Full support will be available, if needed, by putting you in touch with various helping agencies, at the hospice and elsewhere.

**Who will see my information?**

Your information will be handled in the strictest confidence which means that your name and identity will not be used or disclosed at any point. Your views will be gathered collectively and written in the final PhD thesis and in associated articles for academic journals, but you will not be identified by name.

**Will I have to sign anything?**

You will be asked to sign a consent form before taking part in the research (Consent Form Stage 1). After your interview you will be asked to sign a second consent form regarding whether or not you agree to direct quotations of your words being used (Consent Form Stage 2). You will be given a copy for your records.

**What if there is a problem?**

If you have a concern about any aspect of this study, you may wish to contact the researcher, Susan Walker, via email at [s.walker@ilcs.keele.ac.uk](mailto:s.walker@ilcs.keele.ac.uk) or by post at Susan Walker (PhD Student)  
RI for Social Sciences,  
Claus Moser Building,  
Keele University, ST5 5BG.

If you remain unhappy about the research and/or wish to raise a complaint about any aspect of the way that you have been approached or treated during the course of the study please write to Nicola Leighton who is the University's contact for complaints regarding research at the following address:-

Nicola Leighton  
Research Governance Officer  
Research & Enterprise Services  
Dorothy Hodgkin Building  
Keele University  
ST5 5BG  
E-mail: [n.leighton@uso.keele.ac.uk](mailto:n.leighton@uso.keele.ac.uk)  
Tel: 01782 733306

**What happens next?**

If you would like to take part in this research, by having an interview with Susan Walker, please return the attached reply slip in the enclosed self-addressed envelope, or email Susan at the above address. Susan will then contact you to arrange a convenient time and place to meet.

**If you decide to take part, please reply by 31<sup>st</sup> January 2012**





RESEARCH INSTITUTE FOR LIFE COURSE STUDIES

Research Participant Consent Form  
Stage 2

Consent Form (2)

Preferred Place of Death - One UK Hospice Perspective

Please  
tick one box

1. I am happy for direct quotations to be used

2. I wish to see any quotations before agreeing to their use

3. I do not agree to quotations being used.

\_\_\_\_\_  
Name of participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature



## Appendix 5

### RESEARCH INSTITUTE FOR SOCIAL SCIENCES

Preferred Place of Death: One UK Hospice Perspective  
Focus Group 024/06/11

lpm

Douglas Macmillan Hospice, Stoke-on-Trent

### **Further Support**

This topic is a sensitive one and that it may be that after the focus group, you would find it valuable to talk about this further with helping agencies at the hospice or elsewhere:

- Hospice staff support network can be accessed through the hospice intranet
- The hospice chaplains can be accessed at their office
- *Macmillan Cancer Support* can be accessed via their helpline 08001234 or the website [www.cancerbackup.org.uk](http://www.cancerbackup.org.uk)



**RESEARCH INSTITUTE FOR SOCIAL SCIENCES**

**Preferred Place of Death – One UK Hospice Perspective  
Focus Group Schedule**

**024/06/11 1pm, L3 Education Centre Douglas Macmillan Hospice, Stoke-on-Trent:**

**Introduction:**

Introduce self and HP

Participants to introduce themselves and role

***To the study***

The researcher will explain that she is aware that this topic is a sensitive one and that it may be that after the focus group, the participants would find it valuable to talk about this further with helping agencies at the hospice or elsewhere:

- Hospice staff support network can be accessed through the hospice intranet
- The hospice chaplains can be accessed at their office
- *Macmillan Cancer Support* can be accessed via their helpline 08001234 or the website [www.cancerbackup.org.uk](http://www.cancerbackup.org.uk)

***To the process***

Check that everyone has completed a consent form. There will be a second consent form at the end which gives you the option for direct quotations of what you've just said to be used or not.

Briefly explain that the purpose of this discussion group is to explore the topic of preferred place of death of hospice patients from a hospice staff perspective. This includes exploring professional factors that may support of negate patients' choices about where they are cared for at the end of life.

The Focus group will last for no more than one hour.

**ASK:** Does anyone have any questions? Does anyone object to me turning on the tape recorder?

***Focus Group Questions***

- 1. Can you describe what kinds of difficulties you may have had as a professional in supporting patient choice?**
  - a. What factors do you as a professional think influence patient choice?
  - b. How might families influence these issues?
  - c. Have you received any training/education around patient choice?
  
- 2. The government End Of Life Care Strategy (2008) suggests that patients' preferences should be ascertained, documented and reviewed. What do you think/ feel about this statement?**
  - a. Do you think this issue is important?
  - b. Is it realistic to document and review these choices?
  - c. When do you think is the appropriate time to raise this with patients?
  - d. Who might be the appropriate person to raise this issue?
    - a. Should questions around preferred place of death be asked routinely?
    - b. Where do you feel patient preferences should be documented (if at all)?
  - a. How should such information be communicated across the care team?
  
- 3. Have you ever been involved in discussions around preferred place of care?**
  - a. Were these discussions with patients?
  - b. Were these discussions with families?
  - c. Were these discussions with colleagues?
  - d. How often might you have these discussions?
  
- 4. What kinds of conversations have you had with patients on this issue?**
  - a. In what way(s) did you find this topic easy to raise and talk about?
  - b. In what way(s) did you find this topic difficult to raise and talk about?
  - c. Where did you record these discussions?
  
- 5. What kinds of conversations have you had with colleagues on this issue?**
  - a. In what way(s) did you find this topic easy to raise and talk about?
  - b. In what way(s) did you find this topic difficult to raise and talk about?
  - c. Where did you record these discussions?
  
- 6. In your experience do patients have preferences?**
  - a. If so under what circumstances do they tell you?
  - b. Under what circumstances do you bring up the subject?
  - c. How did it feel to talk about this?
  
- 7. What are your thoughts on ascertaining preferred place of death for hospice patients?**



- a. Do you think that hospice patients currently die in their place of choice?
- b. What factors do you think might influence this?
- c. In what way(s) might this be a difficult issue for you as a professional to talk about?
- d. What factors do you feel might affect this?

That concludes my questions for this discussion. Does anyone else have anything they would like to add about the issues we have discussed today?

Thank participants for sharing their views, giving their time, and ask them if they agree to you turning off the tape recorder.

**NB Remind participants that if they need to talk further about this issue then support can be accessed from the various helping agencies at the hospice and elsewhere, which the researcher has mentioned previously.**

## Preferred Place of Death – One UK Hospice Perspective Patient Interview Schedule

1. **Introduction:** Introduce self to participant
2. **Consent Form Stage 1**
2. **Intro to the study**

I'm aware that this topic might be a sensitive one for you, because we'll be talking about death and dying. So it may be that after the interview, you'd find it valuable to talk about this some more with helping agencies at the hospice or elsewhere. So this sheet gives you some contact details of people you could contact for help if you need it – you might not need to but here are the phone numbers just in case.

  - Dayhospice staff can be accessed by phoning 01782 344 300
  - The hospice chaplains can be accessed by phoning 01782 344 300
  - *Macmillan Cancer Support* can be accessed via their helpline 08001234 or the website [www.cancerbackup.org.uk](http://www.cancerbackup.org.uk)
3. The purpose of the interview we're going to do today is to explore your views about preferred place of death for hospice patients, such as whether patients do choose a place where they would like to die or not and the reasons for that.

The interview will last for between 30 – 60 minutes. And we can stop at any time if you feel you need to, just ask me to stop the interview.
4. **To the process:** Check that the participant has completed a consent form. Explain that there will be a **second consent form** at the end which gives you the option for direct quotations of what you've just said to be used or not.

**ASK:** Do you have any questions? Can I turn on the tape recorder?

## Interview Questions

1. **Let's begin with a few details:**
  - Would you mind telling me your age? (Gender !)
  - How would you describe your ethnicity (white British, black British; Black Caribbean)
  - Are you married/single/living with a partner/widowed?
  - Is your particular diagnosis a cancer or non/cancer diagnosis?
2. **Tell me how you use the hospice?**
  - When were you referred to the hospice and by whom?
  - Was the hospice what you expected – why/why not?
  - In what ways (if any) has the hospice helped you live with your illness?
  - Tell me about what your life is like now (as you live with your illness)
3. **Tell me what your spouse/partner/family think about your going to the hospice.**
  - Has your going to the hospice helped them and if so what ways?
4. **Do they talk much about death and dying at the hospice? Have you**
  - Have **you** had any conversations about it?
  - If so who did you talk to?
  - How was that for you ? e.g. hard/helpful/easy/a relief/upsetting
5. **In particular I'd like to ask you about the place where you might want to die. We know that some people do think about this. If YOU had a choice do you know where you would choose? (and why?)**
6. **Is this something you have thought about before today?**
  - Have you already been asked about this by someone else?
  - Who asked you?
  - Were your wishes written down?
  - How did that go for you?
  - How confident are you that you'll get your choice?
  - Did you do anything else about it – write it down/talk to someone else?
7. **For you, who would (did) you find it helpful to talk to about this and why?**
  - Hospice nurse/doctor/social worker/chaplain/GP/hospital doctor
  - Family member/spiritual adviser
8. **At what point might you want to talk to someone about your preferred place of death? Give reasons why?**
  - When first diagnosed
  - At Day hospice (when feeling well)
  - On admission to hospice in-patient unit
  - Leave it as late as possible

9. **Do you think you might need to have more than one conversation about this and if so why?**
- As circumstances change preference may change – not set in stone
  - It's such a hard topic one conversation would be more than enough
10. **Do you have any questions you'd like to ask someone about choosing a place for death e.g.**
- What are the options?
  - Will I get my preference
  - What can I do about recording my preferences?
11. **What kinds of things might be important to you when thinking about a place of death? e.g.**
- **Home for familiar surroundings**, own furniture, see the dog, control who sees you, watch TV; **family atmosphere**, carrying on as normal, make it **easier for rels.**
  - not at home to save the **family** burden of care, or spare them **memories of your death** in a particular room, or worries about **symptoms and care needs**, you may feel safe in the hospice or hospital
  - **Spiritual and/or religious care** and/or rituals
12. **Could you see yourself talking about preferred place of death to members of your family? Why/Why not?**
- Would you find this easy/difficult and why?
  - How do you think they would react?
  - In your opinion is it important to talk about this within families why/whynot?
  -
13. **Is there anything else you would like to talk about today on this issue?**

Thank you. That concludes our interview.

Reminders:

1. If you want to talk about this further or get some support, details of people who can help you are on the printed sheet.
2. Sign Consent Form 2 regarding direct quotations

## Appendix 8 Permission From Journals To Use Published Articles

Email correspondence from editor of *International Journal of Palliative Care*

regarding use of the following articles in the thesis:

Walker, S. and Read, S. (2011) Accessing vulnerable research populations: an experience with gatekeepers of ethical approval. *International Journal of Palliative Nursing*. 17 (1), pp. 14-18.

Walker, S., Read, S. and Priest, H. (2011) Identifying, documenting and reviewing preferred place of death: an audit of one UK hospice. *International Journal of Palliative Nursing* 17(11), pp.1-7.

**To:** Susan Walker <[s.walker@keele.ac.uk](mailto:s.walker@keele.ac.uk)>

**Date:** Monday, 18 August 2014 15:18

**From:** ijpn <[ijpn@markallengroup.com](mailto:ijpn@markallengroup.com)>

**Subject:** Using articles in PhD thesis

Dear Sue,

Thank you for your email. You can use the versions that were accepted for publication, but not the final published versions. I hope that's OK.

Kind regards,

Craig

**Craig Nicholson**

*Editor, International Journal of Palliative Nursing*

---

International Journal  
of Palliative Nursing

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Jude's Church, Dulwich Road, London, SE24 0PB, United Kingdom

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Email correspondence from editor of *Qualitative Methods in Psychology Bulletin* regarding the use of the following article in the thesis:

Walker, S., Read, S. and Priest, H. (2013) A researcher's experience of focused coding in grounded theory: What makes the final cut?. *Qualitative Methods in Psychology Bulletin* 15 (Spring) 2013.

**To:** Susan Walker [mailto:[s.walker@keele.ac.uk](mailto:s.walker@keele.ac.uk)]

**Sent:** 20 August 2014 15:57

**From:** Simon Goodman <[aa4592@coventry.ac.uk](mailto:aa4592@coventry.ac.uk)>

**Subject:** From Sue W: QMiP Permission

Dear Sue,

Thanks for your email. I've checked the rules about this and I've been told that " You can reproduce the Bulletin material as long as you state that it was first published by The British Psychological Society and then to include the name and date of the publication" so it should be quite straightforward.

Best wishes,  
Simon

\*\*\*\*\*

Dr Simon Goodman  
Research Fellow

Centre for Research in Psychology, Behaviour and Achievement, Coventry University  
[S.Goodman@Coventry.ac.uk](mailto:S.Goodman@Coventry.ac.uk) \*\*\*\*\* Tel: 02477659515 \*\*\*\*\* Profile and full address  
QMiP Bulletin editor \* Applied Psychological Research editor \* Twitter \* Research Gate

Email correspondence from editor of *Nurse Researcher* regarding the use of the following article in the thesis:

Walker, S., Read, S. and Priest, H. (2013) Use of reflexivity in a mixed-methods study. *Nurse Researcher* 20 (3): 38-43).

**To:** Susan Walker [mailto:[s.walker@keele.ac.uk](mailto:s.walker@keele.ac.uk)]

**Sent:** 18 August 2014 15:14

**From:** Helen Hyland

**Subject:** Citing/using article

Dear Sue

This is to advise you that copyright permission has been granted for your request below.

**Please note:** The articles should be fully acknowledged with name of the author and the relevant ***Nurse Researcher*** details.

Please send me your full postal address to enable me send you the signed copyright release form.

Kind regards

Helen

***Helen Hyland***

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