

**CLINICAL THINKING, KNOWLEDGE AND THE  
REFERRAL PRACTICES OF CONSULTANT  
PHYSICIANS TO SPECIALIST PALLIATIVE CARE  
SERVICES - AN INTERPRETATIVE  
PHENOMENOLOGICAL ANALYSIS**

**Thesis submitted for the degree of  
Doctor of Philosophy**

**by  
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## SUMMARY

### **Aim and research questions:**

The aim of the study described in this thesis was to explore the personal and professional experience of consultant cardiologists, oncologists and old age psychiatrists and the consequent impact on referral practices to specialist palliative care services. The research questions attempted to develop an understanding of the relationship between their perceptions of and attitudes to palliative care and consequent decision making.

### **Methods:**

The chosen methodological approach was interpretative phenomenological analysis (IPA) which supported exploration of the consultants experience together with facilitating their understanding of their idiographic experience. Ten minimally structured individual interviews were conducted with four cardiologists, four oncologists and two old age psychiatrists. Consistent with the philosophical approach of IPA their individual experiences were analysed – descriptively, conceptually and linguistically. The experiences of each consultant group were then combined to elicit their shared experience before being compared across groups.

The work was interpreted by detailed discussion which considered the structural context, the influence of the macro, meso and micro levels of health care and the political, historical and clinical aspects of palliative care on their experience. Deeper exploration was undertaken by considering the phenomenological concept of the life-world, 'habitus' and the philosophical and theoretical contexts of knowing and clinical thinking. The use of language and specifically metaphor supported increased understanding.

### **Findings:**

The consultants' experiences (both personal and professional) reflected the primacy of their clinical expertise and their uncertainty as to whether a palliative care referral was always in the best interests of their patient group. The requirement for prognostication, identifying the transitions from active to palliative care was especially problematic for heart failure and dementia patients due to the uncertain disease trajectory. Many of the consultants identified the personal cost and clinical dilemmas of determining the end of life. Their stories, in particular identified the difficulties in establishing and communicating an end of life prognosis reflecting their unique personal and professional responsibility as medical consultants which contradicts the perceived contemporary dominance of multi professional working.

## ACKNOWLEDGEMENTS

This study would not have been possible without the active participation of the consultant cardiologists, oncologists and old age psychiatrists who gave freely of their time and engaged with interviews that made them explore potentially personal, sensitive and complex experiences. Without their reflective stories the thesis would not exist.

I also extend thanks to the supervisors who initially engaged with the embryonic development of the thesis, Dr Annette Lankshear, Dr Paul Bennett and Dr Kate Bullen. Dr Lankshear has remained involved throughout. Thanks to her and to Dr Jane Harden, who became my principal supervisor after the first year. Jane has supported, challenged and guided me especially when the PhD journey became a struggle. Both made me believe that studying for and completing this thesis was possible, despite my many uncertainties.

Thank you to Cardiff University School of Nursing and Midwifery Studies who have financially supported my PhD study and to Gail Williams, my manager, who helped me organise and prioritise my workload. My colleague Ben Hannigan, provided advice and challenge especially in relation to the structural contexts of care and in the practical aspects of thesis writing.

My thanks also go to my many colleagues (both at Cardiff and elsewhere) and to Sian Clifton Anna Jones and Christine Wheeler in particular who recognised when times were tough and offered a sounding board for my thoughts and ideas.

My appreciation and thanks also go to Bernadette Coles for her meticulous bibliographic skills, to Gail Sullivan for her invaluable help in transcribing and to Rosemary Williams who, late in the day, helped with editing and proof reading.

Finally without the amazing support of my family Annie (my partner), Ryland (my son), my Mother and late Father this thesis would never have been completed. Especial thanks to Annie who provided me with time and space to work when I know she would rather have been on the golf course.

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## **PREFACE**

My personal experiences of death and dying have, in part, motivated this thesis. My grandmother, who brought me up for the first 6 years of my life, was physically compromised by respiratory and peripheral vascular disease (PVD) following a major heart attack when I was 10. My memories of that time were of her struggling to breathe despite continuous oxygen via a mask. She was largely ignored by the nursing and medical staff. I was forbidden to see her in the last few days and was excluded from her funeral. For many years it made me believe that dying was something to be feared and hidden.

Nearly a decade later my first ward placement as a nurse was on a ward that specialised in acute haematology and general medicine, where care for those who were curable was the primary focus. Those who were dying were treated with caution and uncertainty. Although most were aware of their impending death, the level of support for them was compromised by a lack of professional knowledge and skill. For me it was this group of patients who presented a challenge and provided me with an awareness of my own lack of knowledge. Although I always felt able to talk with them about their fears and anxieties, other skills such as symptom control were more embryonic.

This was a revelation and appears to have set the plan for my future career being involved in the care of all people with life-threatening illnesses, whether malignant or non-malignant diseases.

My father was diagnosed with Parkinson's disease in 1990 just as I was appointed as a Clinical Nurse Specialist in Palliative Care. It was a post which offered a service to both cancer and non-cancer patients. This proved difficult for the hospital staff as they had a cancer-centric and embryonic view of palliative care. Ten years later after a major heart attack and successful resuscitation, consequent heart failure added to his illness burden. He never acknowledged that his life was threatened but, in 2009, he gave my sister and I Medical Power of Attorney providing we ensured he was resuscitated.

In the summer of 2010, due to increasing physical frailty, he had a major fall which caused a brain haemorrhage and a period of mental confusion. We planned for the worst and talked about institutional care. He rallied and became more coherent. I later visited him and we had a difficult discussion, which in retrospect I feel so privileged to have had, in which he stated that he was 'so very tired and had had enough'.

As a family we talked with his medical team and a Do Not Attempt Resuscitation Order (DNAR) was agreed, with the focus of care subsequently being to keep him comfortable. In August 2010 he became breathless and collapsed, dying peacefully. For us it was sad, but tempered with relief in that we felt it was how he planned it, how he wanted it to be.

These reflections have commonality. The themes emerging relate to death being a natural part of living that it is not death itself but the process of dying and the care provided that makes a difference to all involved.

# **CLINICAL THINKING, KNOWLEDGE AND THE REFERRAL PRACTICES OF CONSULTANT PHYSICIANS TO SPECIALIST PALLIATIVE CARE SERVICES - AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS**

## **CHAPTER ONE - INTRODUCTION**

**Dying is a natural process which in a civilised society should be supported with good palliative care. (Royal College of Physicians 2007:vii).**

### **1.1 INTRODUCTION TO THE THESIS**

This thesis is about specialist palliative care with particular emphasis on identifying the factors that may contribute to the referral practices of medical consultants to Specialist Palliative Care Services (SPCS) in Wales. It will compare their referrals in relation to patient populations suffering from advanced cancer, heart failure and dementia. The study will, *inter alia*, consider clinical factors such as diagnosis, disease trajectories and prognostication, models of service provision and patient characteristics. It will also look at physician related issues especially focussing on the consultants' personal experiences of death and dying and how these impact on their relationships and the support offered to their dying patients. In particular it will explore how the consultants exercise clinical thinking, knowledge in practice and the decision-making process.

Underpinning this investigation are philosophical, phenomenological and psychological theories, these include the concepts of knowing, the life-world, judgement-based care and clinical mindlines. The study will also attempt to understand and interpret the physicians' language and its influence on 'meaning making'. At a clinical level it will focus on the complex and unpredictable nature of end of life care.

It will also consider the structural context of 21<sup>st</sup> century healthcare together with the influence of strategic, organisational and operational factors on the provision and delivery of end of life care and specialist palliative care. Strategic factors include both organisational and United Kingdom (UK) national level policy. In considering the organisational level, this thesis explores where local voluntary, statutory, professional and patient bodies

influence and plan for service delivery as well as those operational factors which influence the day to day clinical care for the individual patient or groups of patients.

## **1.2 WHY STUDY THE FACTORS INFLUENCING PHYSICIANS REFERRAL DECISION MAKING TO SPECIALIST PALLIATIVE CARE SERVICES?**

The relevance of this thesis has been reinforced by current national and global end of life and palliative care strategies mandating improved access to SPCS for both cancer and non-cancer patient populations (Department of Health (DH) 2008, 2010a, 2011a; Welsh Assembly Government (WAG) 2008; 2009a). Palliative care services have been described as needing ‘to be available for diseases other than cancer and offered based on need rather than diagnosis or prognosis’ (World Health Organisation (WHO) 2011:1). Therefore the increasing political awareness of end of life care underlines the importance of this exploration of referral practices and validates its selection for doctoral level study.

It is acknowledged that care of people at the end of life (whether the diagnosis is a cancer or non-cancer illness) is a measure of the nature and compassion of our society. This is therefore an important area of study both from an ethical and professional perspective.

A Working Party report published by the Royal College of Physicians (RCP) (2007) argues that palliative care is relevant for most physicians and that it requires a fundamental shift in attitude from seeing death as a failure towards acknowledging it as a natural part of life. RCP members are encouraged to provide care that is both responsive and informed. In practice it is often the consultants who are seen as the ‘gatekeepers’ to SPCS by supporting or restricting referral and thus the focus of the study will be the experiences of those consultants.

The UK General Medical Council (GMC) guidance on end of life care, adopted in July 2010, supported and extended the RCP recommendations (2007). It

specifically states that doctors must ensure that impending death should be made:

An explicit discussion point when patients are likely to die within 12 months, and that medical paternalism on the subject, however benignly intended, must be replaced by patient choice (Bell 2010:312).

Their advice is consistent with the previously outlined policy initiatives, these highlight the need for health professionals to recognise patients coming towards the end of their life to ensure the appropriate transition from active to palliative approaches to care (DOH 2008; Boyd & Murray 2010; GMC 2010).

This research will compare cancer and non-cancer patient populations. By developing an understanding of referral practices we might be able to describe the relationship between physician perceptions and attitudes towards palliative care and how this relates to referral decisions.

Two of the RCP's recommendations resonate, in particular, with the aims and focus of this thesis. Firstly, in relation to referral they state:

Referrals are often made late, when patients have multiple problems and significant distress. Clinicians must recognise that end-of-life care does not mean that someone is going to die imminently but that the approach to their care should change (RCP 2007:xi).

Secondly the report articulates the need for research to inform practice in the precise area of this study's focus:

In order to improve access and equity of provision, research is needed into the development and evaluation of new approaches to the clinical assessment of need for palliative care in the context of uncertain prognosis in a range of diseases and care settings. Identification of clear triggers for referral throughout the course of an illness, where there is evidence of benefit from palliative care services, is important (RCP 2007:xiv).

For cancer patients' palliative care appears to be routinely offered, often irrespective of actual need given that many patients were well managed by generalist providers. For this group, referral was not restricted to those who met the written criteria for those with more complex and intractable problems

(National Institute of Clinical Excellence (NICE) 2004). This positive finding may be related to the historical evolution of palliative care which has been accepted as relevant to cancer, a patient group for whom the diagnosis of the dying phase is often more easily identifiable. Service developments have been largely influenced by the cancer-focussed charitable sector such as Marie Curie Cancer Care and Macmillan Cancer Relief (National Council for Palliative Care (NCPC) 2006a). Consequently, the needs of cancer patients are more likely to have been met in comparison to those with other life-threatening conditions. Evidence supports the premise that clinical diagnosis impacts on access to services and that this results in unmet needs amongst non-cancer groups (Addington-Hall & Higginson 2001; NCPC 2003; Audit Scotland 2008; WAG 2008).

Recent evidence from the Palliative Care Funding Review for England recognised that almost 100,000 terminally ill people 'do not get proper palliative care' (DH 2011a:6). The authors estimate that in England between 70-80% of all deaths irrespective of diagnosis are likely to need palliative input and the median estimate is therefore that around 355,000 people will require palliative care every year. The equivalent figures for Wales are not yet available but are likely to present a similar picture of unmet need. Government priorities currently focus attention on non-cancer patient populations.

One of the reasons suggested for the lack of palliative care input to those with a wider range of conditions is their uncertain disease progression or trajectory. It is for this reason that this study seeks to compare consultant oncologists who, evidence suggests, are dealing with individuals where the timeline is easier to predict, with consultants working with people suffering from dementia, neurological disease and heart failure where there is greater difficulty in 'diagnosing dying'. This comparative approach is supported by the increasing importance and profile of these patient populations in strategic documents and operational guidelines (WHO 2011).

The important areas for exploration reflect the macro (strategic and national policy), meso (organisational and service development) and micro (operational and service delivery) levels of health and social care provision (Mohan 1996; Pilgrim & Rogers 1999; Griffiths 2003). At a macro level the thesis is supported by national strategic documents which recommend equity of access to palliative care for all patients at the end of life. At the meso level University and Local Health Boards, statutory and voluntary providers are working together to develop more inclusive and patient-centred palliative care services. At the micro level practitioners are attempting to work with people at the end of life whose disease journey is characterised by complexity and uncertainty. This third level is the main focus of the thesis but will not consider service user perspectives. The macro and meso levels of health care will provide contextual background to the exploration and discussion.

### **1.3 THE RESEARCHER: AN INTRODUCTION**

Professionally this study has been motivated by my clinical concerns, over more than thirty years in practice, related to the apparent lack of access by non-cancer patient populations to specialist palliative care services and reflects my observation that sub-optimal care is frequently offered to those with advanced dementias and progressive neurological, respiratory and cardiac conditions. The experience of patients and their families was often very distressing, with uncontrolled symptoms and lack of preparation for impending death. This always felt professionally troubling, unsatisfactory and unethical.

### **1.4 THE RESEARCH QUESTION**

After extensive reflection and reading, the following research questions were developed:

1. Is there a significant relationship between physicians' perceptions and attitudes towards palliative care and their referral decisions?
2. What is their view of the appropriateness of palliative care for differing populations?
3. Is there a difference between those consultants working with cancer patients and those with non-cancer patient populations?

However, the iterative nature of the research process adopted led to the gradual evolution of more focussed questions. Preliminary analysis of the first two cardiologist interviews led to the emergence of unexpected elements related to their personal experiences, knowledge bases and to the clinical context. Thus the concept of 'clinical mindlines' emerged, with the suggestion that the decision to refer or not was contingent on explicit knowledge (Gabbay & leMay 2011).

At this time it became clear that my professional colleagues' personal experiences of death and dying (their personal knowing) had a considerable impact on how they related to their dying patients and the support they were able to offer. In particular it influenced how they exercised clinical judgement and made decisions. Little research has been undertaken as to how past personal experience of death and dying impacts on the professional role. There is however a body of literature that relates to the impact of concurrent events (imminent death of a loved one or being newly bereaved) on the care of dying patients (Lowry 1997; Jackson et al 2005).

It is these elements of the thesis together with my own professional and personal experience that clearly link with the chosen philosophical and methodological approach – Interpretative Phenomenological Analysis (IPA) outlined by Smith et al (2009).

## **1.5 THEORETICAL CONSIDERATIONS**

From its inception in the early twentieth century Phenomenology has become recognised as a way of investigating and understanding human experiences in health care research. There are a number of variations and approaches to its use. Phenomenology is both a research method and a philosophy whose evolution has been influenced by the perceived need for rigour in qualitative research. Phenomenology was developed into a more interpretative approach by Gadamer and Heidegger that encouraged activity which looked beyond the individual data by considering the context.



The theoretical perspectives which have influenced this study are combined in the qualitative research methodology of IPA with its focus on three elements: Heideggerian phenomenology (Giorgi 1995), Gadamerian hermeneutics and symbolic interactionism (Denzin 1995) to inform its approach (Smith et al 2009).

Heideggerian phenomenology is derived from the philosophical science of consciousness which focuses on how things appear to us as individuals and in our experience, and how we perceive and talk about objects and events. Hermeneutics is the branch of philosophy that is concerned with the study and interpretation of human behaviour, structures of society, and how people function within these structures. Symbolic interactionism is concerned with individual meanings which are only accessible through an interpretative process that acknowledges the complexity of individual experience when living in the world.

IPA has been derived from these perspectives and supports the idiographic approach and twofold interpretative activity in uncovering and interpreting meaning. Thus its focus is on the subjective individual experience that is interpreted and reflected on by both the participant and the researcher and forms the analytical account (Brocki & Wearden 2006).

Hermeneutic phenomenology is described as having both descriptive and interpretive elements, so IPA allows many different phenomenological stances to be incorporated into one approach. It gives a structured framework to validate the practical application of phenomenology, although it still is difficult to identify what is important in the individual experience and does not seek to make generalisations. IPA attempts to combine opposing schools of thought in phenomenology and is helpful in supporting a pragmatic but robust approach to an appropriate and meaningful application of phenomenology.

Another important aspect of IPA is its focus on language as an important element of the interpretative activity of making meaning of the participants' experiences. In the initial stages of this thesis language was cursorily

considered but as the exploration of the participants' experiences progressed it became clear that it was an important aspect in achieving understanding and providing a useful adjunct to the analysis. The participants' language did not merely reflect their experience but was also a way of achieving a shared understanding. In this it is unlike discourse analysis which has its focus on the use of language as a social performance (Willig cited in Smith 2008).

## **1.6 THE STUDY**

The process of doctoral study followed a series of stages which are presented in Appendix 1. The production of the PhD thesis has been characterised by a 'roller coaster' experience with periods of intense activity particularly since June 2010. Earlier engagement was affected by external events necessitating lack of involvement for a prolonged period between late 2007 and early 2009 and again between September 2009 and June 2010 when data collection started. Changes in primary supervisor also had an impact that, on reflection, was helpful; the first supervisor's approach was appropriate and enabling, supporting the development of the research focus, proposal and choice of methods - the 'thinking and planning' part of the thesis. The second primary supervisor's approach was equally apposite in supporting and challenging the 'doing' of the thesis, in making it happen and in broadening my theoretical and philosophical horizons. Constancy has been maintained throughout by the same second supervisor being present.

The research reported in this thesis explored the experiences of consultants working in secondary care with patients in three patient population groups: advanced Cancer, Heart Failure (HF) and advanced progressive Neurological Disease (APND) such as Multiple Sclerosis. Subsequently specialists in APND were replaced by old age psychiatrists dealing with people with dementia. This change was made because of the unwillingness of neurologists to participate. The reasons for this were given as heavy workloads and lack of time. On reflection the inclusion of old age psychiatrists was fortuitous due to the increasing strategic profile of dementia and the perceived needs of dementia patients at the end of life (Welsh Government (WG) 2010; WHO 2011).

The study sought to explore consultants' experiences in relation to the pattern of referral of their patients to SPCS. Through minimally structured interviews and meticulous data analysis it firstly sought to discover their individual (idiographic) experience and then moved on to identify the shared experience of each consultant group. Subsequently it sought to establish patterns and connections between all the consultants across the three groups. Finally it identified a unique element of one individual's experience - a 'little gem' that provided rich data (Polkinghorne 2004).

The aim of this thesis is to locate the participants' experiences within theoretical frameworks that contributed to informing and understanding their referral practices in end of life care. The findings from the study will be made known in journal articles and other publications (one article in relation to personal experiences impacting on clinical practice in end of life care is already in preparation) and by national and conference presentations. It is also envisaged that the outcomes of this research will be presented to the Palliative Care Implementation Board of the Welsh Government and may impact on models of service delivery and professional education and support. It is hoped that areas for further research will evolve, especially related to developing clinical mindlines to support care at the end of life.

## **1.7 ORGANISATION OF THE THESIS**

I have divided the thesis into four parts. The first part sets the scene for the study and provides the structural and theoretical context. Part two explores and describes the participants' stories and experiences from an idiographic and shared perspective. The third part interprets and discusses their experiences, locating the work within the wider concepts of practice, clinical thinking, knowing and decision making. The final part of the thesis offers an evaluation of the study together with my experiences of the PhD journey.

## **PART 1: BACKGROUND TO THE STUDY**

### **CHAPTER TWO - STRUCTURAL CONTEXT: SPECIALIST PALLIATIVE CARE.**

**All people have a right to receive high-quality care during serious illness and to a dignified death. (WHO 2004a).**

#### **2.1. INTRODUCTION**

This chapter provides a scene setting and contextualising framework that locates the thesis within contemporary health and palliative care practice. It will also explore the current literature related to patient and professional perspectives of palliative care. Smith et al (2009), when discussing the writing of IPA theses, suggest that it is not always necessary for a formal literature review to be part of the structure. However, for this thesis, a literature review enabled me to be more focussed. It identified elements and themes in the literature which informed the interview questions, the reciprocal approach adopted in engaging with the participants and in dealing with their narrative data. It also identified theoretical frameworks which support the discussion as outlined in the second part of the literature review in Chapter 3.

In supporting the approach adopted in the introductory chapter, this chapter will explore the associations between the macro, meso and micro levels of health care evidence that inform and sometimes complicate professionals' practice in end of life care. Palliative and end of life care is supported by a large amount of literature. It is the focus for much strategic and organisational policy development both nationally and globally, being influenced by voluntary organisations supporting patient and family perspectives and intense media attention.

Whilst utilising research evidence from the United States it is important to acknowledge their different approach to end of life care provision. As in the UK hospice is primarily a concept of care, not a specific place of care. It offers a comprehensive program of care to patients dealing with a life threatening illness in the last months or days of their life. Uniquely in the United States healthcare practices are largely defined by the Medicare

system, a social insurance programme, and other health insurance providers. Thus hospice care is made available in the United States to patients of any age with any terminal prognosis who are medically certified to have less than six months to live and who agree to forgo curative interventions. Thus many physicians are slow to refer to hospice care, waiting until they are absolutely certain of a terminal prognosis. Some physicians believe that the patient *must* have a six month prognosis or less to receive hospice care, while others are overly optimistic in their assessment of prognosis, presuming treatment will be more effective than it is (Christakis 1999, Kuebler et al 2006). As a result, the majority of patients are referred to hospice in the very end-stages of their diseases. This six month requirement has influenced much American work on disease trajectories and prognostication (Christakis 1999; Teno et al 2001; Lunney et al 2002; Lynn & Adamson 2003) which is discussed in sections 2.4 and 2.5 of this chapter. The study populations and context are very different from that in the UK but were important to include in the literature review as they have provided the impetus for more recent UK initiatives that suggest access to SPCS should be linked to the identification of the last year of life (Gold Standards Framework 2006). This requirement supports contemporary criticism by patient and carer groups that death is becoming increasingly medicalised and technological.

Almost on a daily basis, new initiatives in the international and national news have the potential to relate to this study. Examples include the UK healthcare policy focus on dementia, and Terry Pratchett's high profile advocacy for the Alzheimer's Society which has rekindled the debate related to Physician Assisted Suicide and complex issues associated with a diagnosis of dementia and end of life.

The literature search strategy was supported initially by a wide-ranging systematic scoping search (see Appendix 1) which included accessing eight health and social science electronic databases: MEDLINE (Ovid); the Cumulative Index of Nursing and Allied Health Literature (CINAHL); the Allied and Complementary Medicine database (AMED); EMBASE; British Nursing Index (BNI); Clin Psych; EBSCO and PubMed. The scoping approach

enabled the identification and evaluation of the large amount of literature available which initially appeared daunting, but 'endnote' enabled the identification and removal of duplicate references. This time consuming process was supported by guidance from a librarian colleague whose expertise in accessing evidence in support of systematic reviews ensured a robust approach. Subsequent hand searching of the abstracts retrieved was undertaken to identify the specific references which linked with the themes and aims of the study. Further literature was accessed through backward chaining.

Daily ZETOC alerts were set up following the initial search process using the themes identified to ensure the thesis continued to be informed by current evidence and opinion. Literature was accessed until the end of November 2011.

## **2.2. PALLIATIVE CARE IN CONTEXT: HISTORICAL AND POLITICAL PERSPECTIVES.**

### **2.2.1 Setting the scene**

Palliative care is described as 'an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual' (WHO 2002, 2010). This WHO definition replaced an older definition that was restricted to patients 'whose disease is not responsive to curative treatment' (WHO 1990). Subsequent WHO definitions extend the scope of palliative care to patients and families 'facing the problems associated with life-threatening illnesses' and avoids the focus on specific diseases (WHO 2002, 2010). It indicates the importance of the active professional role and responsibility, across all care settings, in relation to impeccable assessment skills involving a range of supportive interventions including symptom control, psychological support therapies and complementary therapies for patients and their families (Sepulveda et al 2002). The term 'life limiting (threatening) illness' moves the focus beyond cancer to illnesses that:

can be reasonably expected to cause the death of the patient within a foreseeable future. This definition is inclusive of both a malignant and non-malignant illness. Life limiting illnesses might be expected to shorten an individual's life. This differs from chronic illnesses where, even though there may be significant impact on the patients' abilities and quality of life, there is likely to be a less direct relationship between the illness and the person's death. (Palliative Care Australia 2005:6).

Palliative care advocates an approach to care which is person-centred and based on neither diagnosis nor prognosis but on patient and carer needs (Boyd & Murray 2010). Specialist palliative care (SPC) focuses on people with the most complex needs (physical and psychosocial) whatever their diagnosis and is provided by professionals who specialise in palliative care. Specialist teams also provide support, guidance and education for generalist practitioners who care for the majority of patients at the end of life with less complex needs. These services have great proficiency in caring for people with cancer but less expertise in caring for those dying from other diagnoses.

Palliative care is a term used mainly by professionals, providers and patients whereas the term 'end of life care' has been predominantly linked to UK strategic and political initiatives. For this thesis, reflecting the macro, meso and micro levels of health care impacting on referral practices, 'end of life care' (EoLC) will be used interchangeably with 'palliative care' reflecting their shared understanding. The term 'terminal care' will not be used, as currently it is only used to describe care in the last days of life.

Table 1: Chronology of terms associated with caring for dying people:

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|---|
| <ul style="list-style-type: none"><li>▪ Hospice care</li><li>▪ Terminal care</li><li>▪ Continuing care</li><li>▪ Care of the dying</li><li>▪ Palliative care</li><li>▪ End-of-life care</li><li>▪ Supportive care</li></ul> |
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**Source: Payne, Seymour & Ingleton 2008 p3.**

The proper use and appraisal of specialist palliative care services relies on the belief that its philosophy, ideas and language are commonly understood by all doctors. Evidence suggests that this is not the case. Pastrana et al's (2008) discourse analysis of the terms used in global, national, strategic, operational and research literature reveals a heterogeneity in the definitions of palliative care. In the UK end of life care terminology has developed over time being influenced by historical and service developments. As well as a response to governmental policies and agendas and the need for palliative care to be accepted by mainstream services. Social and health care terminology at the end of life may relate to both in the client groups to be cared for, and in the timing of the involvement of palliative care services during the illness trajectory.

The World Health Organisation (2011) report poses the important question *'Isn't palliative care just good health care'?* Their answer makes the distinction that it is a component of health care that offers a flexible approach to patients and families enabling them to cope with and manage their changing circumstances. 'It is a component of health care that can be needed at any time in life, starting at a low base and rising to eventually become the predominant theme for many people' (WHO 2011:6). It is also a problem-solving approach that offers help as the patient's and family's situation changes and becomes holistically more complex (Lynn & Adamson 2003). The aim of support at the end of life is to enable patients and their families to:

maintain the best quality of life throughout their illness  
and allow people to have a good death, where the  
wishes of the patient and their family are respected  
(Audit Scotland 2008:3).

Thus the unique nature of palliative care might be its flexible, person-centred approach that supports individuals with uncertainty in the context of a major stressful life event (Holmes & Rahe 1967).



In relation to demonstrable outcomes, there is limited evidence that in cancer, specialist palliative care improved symptom control, reduced time spent in hospital, improved patient and carer satisfaction and choice, and reduced overall costs of care (Edmonds et al 1998; NICE 2004; Jack et al 2004; Addicott & Hiley 2011). There is a lack of research evidence regarding efficacy and effectiveness of palliative care services (McWhinney et al 1994; Higginson 1999; Hanks et al 2003; Higginson et al 2003; Simon & Higginson 2009). Kendall et al (2007) highlight methodological weaknesses, ethical sensitivities and practical difficulties in conducting research at the end of life as being factors responsible for the lack of scientific evidence supporting the validity of palliative care services.

There is even less evidence of non-cancer patients benefiting from SPC, with no clarity as to how the previously demonstrated outcomes for cancer are replicated in the non-cancer populations. This may also relate to the lack of research or audit evidence available (Addington-Hall 2002; Addington-Hall et al 2007; RCP 2007; NAO 2008). This rather limited evidence as to the benefits of SPC does not appear to have had a deleterious impact on strategic directives and service developments.

### **2.2.2 Historical and political developments**

Globally there are about fifty-six million deaths per year of which an estimated 60% might benefit from some form of palliative care (Stjernsward & Clark 2003). In the UK, about 1% of the population dies each year. This equates to over half a million people dying each year in England and Wales, almost two thirds of whom are aged over 75 years. Almost three quarters of these deaths are predictable and follow a period of chronic illness such as cancer or heart disease (Office of National Statistics (ONS) 2004, 2010, National Audit Office (NAO) 2008). A high percentage of these deaths are likely to be from causes where people may benefit from palliative care interventions. Higginson (2001) calculated that the number of people requiring palliative care would include all those dying from advanced cancer and two thirds of all other deaths. This would equate to 76% of all deaths in England requiring palliative care. An Australian working party concurs and approximates the population for

palliative care as being between 50-89% of all dying patients (McNamara et al 2006).

Historically palliative care focussed on, and became synonymous with, the care of people with advanced cancer. It was recognised as a specialty for individuals with advanced cancer in 1987, evolving as an approach to care that took over when attempts to control the malignant growth failed, pain had become intractable and a more holistic approach to care was required. In the early 1990's, following health service reorganisation, recommendations were made to widen access to Specialist Palliative Care Services (SPCS) (Welsh Office 1996; National Council for Hospices and Specialist Palliative Care Services (NCHSPS) 1998) whereby all patients needing them should have access to palliative care services.

It was anticipated that the NICE guidance (2004) *Improving Supportive and Palliative Care for Adults with Cancer* would inform the development of effective service models for other groups of dying patients focussing on service configuration and not clinical care. No similar guidance has as yet been commissioned for other diseases. Subsequent political changes in the NHS: the purchaser and provider split, Clinical Governance and National Service Frameworks (NSF's) also supported the extension of palliative care beyond cancer (National Council for Hospices and Specialist Palliative Care Services (NCHSPCS) 1998; NCPC 2003; 2004a; 2004b; DOH 2006; NCPC 2010). The NCPC minimum data sets (MDS) 2004-2005 (NCPC 2006b) illustrated the lack of access to specialist palliative care services for patients with non-cancer diagnoses. They appear to make up only about 3% of the palliative care patient population - these patients predominantly having a neurological or HIV diagnosis.

However in comparing service activity in the last five years there has been a demonstrably small increase in both the percentage and the number of non-cancer patients who have been cared for. This is most striking in the hospital setting where it has increased from 5.9% to 17.3%, while for specialist palliative care inpatient units it has increased from 3.3% to 9.3%. Outpatient

services have the highest percentage increase at 25% (MDS) NCPC 2009-10 (NCPC 2005; 2011). These are still disappointing figures as cancer accounts for only 27% of all UK deaths (Cancer Research UK 2010a). It also does not reflect the strategic intent and direction outlined in governmental, professional and organisational documents which have focussed on palliative care being extended to non-cancer patient populations.

Cancer focussed palliative care services have promoted an understanding of the needs of patients and carers at the end of life and supported the development of the specific knowledge base in relation to pain and symptom control. The needs identified are held in common with people with other life-threatening conditions (Gomes & Higginson 2008). Many guidelines and policy documents have explored whether cancer is unique in relation to end of life care. Most conclude that cancer palliative care is not distinctive and consequently support the National Council for Palliative Care's (NCPC) mission 'to promote palliative care for all who need it' across diagnostic and population groups (NCPC 2004b; 2005; NCPC 2006c; 2006d; 2006e; DOH 2008).

Most referrals relate to the management of complex symptoms and situations especially relating to psychological, family and spiritual distress (Murray et al 2005). Specialist hospital palliative care support teams report that patients with a cancer diagnosis were accountable for 86% of their new referrals in 2009-2010 (MDS); in-patient figures reflected a similar figure of 90% new patients having a primary diagnosis of cancer (NCPC 2011).

Following much inter-organisational collaboration, one of the identified key themes of the End of Life Care Strategy in England is the focus on helping professionals identify people reaching the end of their lives and supporting them with plans for care (NICE 2004; DH 2008; Marie Curie Cancer Care 2009, 2010; DH 2011a). This has influenced many strategic, organisational and operational guidelines related to the resourcing and clinical development of services.

Strategic and political drivers have been instrumental in promoting widening access to palliative care services to the non cancer patient population. Health policy, as stated in various NSFs (DOH 2001; 2005) and Quality Indicator and Improvement Guidance (WG 2011a), makes it clear that palliative care must form an intrinsic part of the range of care in heart disease and Alzheimer's disease, for example. The NAO Survey (2005) '*Tackling cancer*' confirmed inequities in palliative care provision for both cancer and non-cancer patient populations. The most recent end of life policy directives from the four UK governments (WAG 2005; DH 2006, 2008; WAG 2008; WG 2010; Scottish Parliament (SP) 2008a, 2008b; 2009; Northern Ireland Executive (NIE) 2010) focus on improving end of life care where diagnosis is immaterial. All explicitly require practitioners to introduce palliative and supportive care much earlier in the illness trajectory (DH 2000a; NICE 2004; DH 2006, 2010b).

End of life care services are characteristically funded and delivered by a mix of providers from the health (NHS), social (local authority) and voluntary sectors (such as Marie Curie, Macmillan Cancer Support and hospices). Historically this has had an impact on the location of service developments and the cancer centric models of service delivery (NCPC 2006a; NCPC 2006b). Others involved include independent agencies and increasingly individual, family or informal carers (Addicott & Hiley 2011). The contribution and challenges for family and informal carers to care at the end of life is evidenced by their importance in determining place of care and access to specialist services (Higginson & Sen-Gupta 2000; Agar et al 2008; ONS 2010; EAPC 2010a; Warren 2011) and in the cost savings made by their involvement in delivering care (Maher & Green 2002). Little is known about the health economics of palliative care but it is important to bear in mind that, indirectly, a significant proportion of the cost burden of this care will fall on the patient and their carers.

There is little knowledge of the health and social care needs of people at the end of life nor of the cost and resource implications of providing for their care (NAO 2008; Hughes-Hallett et al 2010). The diversity in service provision across settings and sectors can result in significant variation in availability of

and co-ordination between services (DH 2008; 2010a). As a result end of life care can be fragmented and ineffective, making transitions between providers difficult and contributing to patient and family distress, professional concerns and poor clinical outcomes (DH 2008; Gomes & Higginson 2008; Addicott & Ashton 2010; NCPC 2010; Hughes-Hallett et al 2011). This is especially problematic in the acute hospital setting (DOH 2010a; GMC 2010; GSF 2010).

The National Audit Office (NAO) (2008) found that some people approaching the end of their life receive a high quality service, but acknowledge that there is room for improved coordination between health and social care services in planning and delivering end of life care. An investigation of complaints in relation to End of Life Care (EoLC) received by the Healthcare Commission (NAO 2008) identified a number of common issues. These included poor support, inattention to holistic care needs and, of particular relevance to this thesis, concerns related to the shift in the focus of interventions from care to cure which were 'not clearly communicated, leading to needless and painful interventions, that diminished the patient's quality of life, and referrals to specialist palliative care teams were sometimes made too late or not at all' (NAO 2008:16).

Initiatives from a public health perspective suggest that access to SPCS should be based on levels of distress or disease burden rather than diagnostic group (Foley 2003). The contemporary debate continues to be focussed on whether access to palliative care should be needs based or based on diagnostic categories (Skilbeck & Payne 2005). The current tension exists between improving the care of the dying, which was the focus of early palliative care, and the requirement to extend services to those earlier in their illness trajectory, and from a variety of diagnostic groups, with identified significant problems (Payne et al 2008; Hanks et al 2010).

Evidence indicates that the symptom profile, psychological and spiritual distress together with increasing dependence characterises the end of life experience of many individuals dying from conditions other than cancer. Their experiences mirror, in part, the problems experienced by cancer patients at

the end of life. This similarity supports the extension of palliative care beyond cancer. The ethical argument related to the extension of palliative care to the non-cancer patient population is based on justice and equity, on need rather than pathology. As Wasson & George (2001) assert, palliative care should be for all.

The inquiry into palliative care by the House of Commons Health Committee (2004) highlighted inequalities by diagnosis, geographical location and patient demographics, particularly age and ethnicity. Barriers to access to hospice and palliative care have also been categorised as being at societal, organisational, professional, family and individual level (Roscoe & Schonwetter 2006; Gott et al 2011).

In the UK the Welsh Strategic Review of Palliative and End of Life Care (WAG 2008; WG 2009) complements the already published End of Life Care Strategy (DH 2006 and 2008) and the Review of Palliative Care Services (Audit Scotland 2008). Evidence from these strategic documents supports earlier evidence that the availability of specialist palliative care services and the feasibility of accessing them, still varies significantly within each of the UK countries (WAG 2008; WG 2009). The current system of commissioning end of life care needs to encourage more integration of services across providers to meet the needs and preferences of patients within the current financial constraints (Addicott & Hiley 2011). Access is dependent on service availability, funding models and disease status but may also be influenced by patient reluctance and practitioners' unwillingness to refer (Gott et al 2011).

Disease patterns at the end of life are changing, with more individuals dying from chronic debilitating conditions including cardiovascular disease, chronic obstructive pulmonary disease, diabetes, cancer and dementia. Clinically the provision of end of life care is becoming increasingly complex. People with cancer and heart disease are living longer due to improved treatments and interventions. Demand for palliative care services is likely to increase, with demographic changes and an increasingly elderly population living with increasing physical and mental frailty and the consequences of life-

threatening and chronic illness (Gomes & Higginson 2006; EAPC 2009, 2010b). In elderly populations many of these conditions co-exist causing multiple health problems (Addington-Hall et al 1998a, 1998b; WHO 2011).

Thus clinical diagnoses, other than advanced cancer, may act as both a barrier and trigger to referral, specifically relating to the disease trajectories and difficulties in establishing an end of life diagnosis. For example there is evidence of considerable unmet need for those with heart failure and dementia. It also appears that people with a high complexity of need may benefit from access to specialist palliative care services or to professionals with palliative care skills within their existing teams. In their last year of life dementia patients' need for help with activities of daily living and coping at home was greater than for those with cancer (McCarthy et al 1997; NCPC 2009a). Care should be based on needs rather than time or prognosis (Main 2006; NCPC 2009b).

The next part of the literature review considers how clinical diagnoses, disease trajectories, prognostication, patient and physician perspectives impact on referral practices.

## **2.3 CLINICAL DIAGNOSIS**

An overview of each of the diagnostic groups studied in this thesis will be presented in order to identify their unique and complementary needs.

### **2.3.1 Cancer**

In the UK over 309,000 people are diagnosed with cancer each year and it is responsible for over 150,000 deaths. One person in three will develop cancer during their lifetime and of those one in four individuals will die as a primary consequence of their disease. It is predominantly a disease of the ageing population, with 67% of diagnoses made in those over the age of 60 (Cancer Research UK 2009, 2011). More recent analysis by Cancer Research UK (2011) indicates that 40% of people who die prematurely are 'killed' [their choice of word] by cancer, more than those with heart disease and AIDS.

In Wales approximately 15,000 new diagnoses are registered each year, a rate higher than that in England but lower than that in Scotland. The incidence of cancer in men in Wales is the highest of all UK countries. It is one of the two biggest causes of early death in Wales (Cancer Services Coordinating Group, WAG 2006) accounting for around 27% of male deaths and 23% of female deaths. Therefore it remains one of the largest killers in the UK accounting for 24-27% of all deaths (Gold Standards Framework (GSF) 2005; Cancer Research UK 2010a, 2011; ONS 2010).

Cancer is a feared disease thought of as synonymous with death and suffering in the minds of the British public. At diagnosis the clinical progression of cancer is uncertain, its clinical outcomes unpredictable and even for many of those 'cured' the fear of its return adversely impacts on their future (Cancer Research UK 2010b). Kearney et al's (2003) survey of oncology health care professionals (doctors, nurses and radiographers), identified that they also hold negative feelings towards cancer, being especially fearful of being in the cancer situation themselves. Societal attitudes and personal experience appear to prevail over their professional, educational and clinical experiences. Susan Sontag (1989) described her personal situation thus:

When I became a cancer patient ...what particularly enraged me – and distracted me from my own terror and despair at my doctors' gloomy prognosis - was seeing how much the very reputation of this illness added to the suffering of those who had it (p.97).

This appears to confirm the negative perceptions held by many professionals.

For those with cancer referral to palliative care may occur at any stage in their journey where there is perceived need, irrespective of prognosis. Its trajectory is sometimes more predictable in enabling easy identification of 'tipping points', often early in the disease process. Many patients will concurrently receive active and palliative care, the goal being to improve or maintain quality of life.



Ellershaw & Wards (2003) clinical review combined the professional and clinical perspectives of specialist palliative care and cardiology, identifying the differences and similarities in the diagnosing of dying for people with advanced cancer and heart failure. In cancer, predictability of the dying phase is easier. It is rarely precipitous or linked to an acute event such as massive haemorrhage. More commonly it is preceded by a gradual deterioration in functional status with individuals becoming bed-bound, exhibiting a decreasing or fluctuating level of consciousness and reduced ability to take food, fluids and oral medication (Higgs 1999). The identification of end of life or dying in advanced cancer appears more straightforward than for other diseases (Lunney et al 2003).

### **2.3.2. Heart failure (HF)**

In the UK there are approximately 70,000 new cases of heart failure diagnosed in a year with approximately 55% of diagnoses made in men and 45% in women. Around 900,000 people in the UK today are living with heart failure. The NSF for Cardiac Diseases (WAG 2009b) identifies that there are over 45,000 people in Wales aged 45 years and above living with heart failure. The incidence and prevalence of heart failure appears to increase sharply with age, with the average age of first diagnosis being at 76 years. The risk of heart failure is higher in men than in women in all age groups, but there are more women than men with heart failure due to population demographics (Cowie et al 1997; British Heart Foundation 2010).

Heart failure occurs as a consequence of damage to the left ventricle of the heart following myocardial infarction in younger patients; in older patients additional factors are implicated such as hypertension, atrial fibrillation and heart valve disease. It is a disabling progressive and common condition that carries a poor prognosis (Camm & Bunce cited by Margereson & Trenoweth 2010). Typical heart failure trajectories include the risk of sudden death, but it is more usually characterised by periods of stability interrupted by acute exacerbations (Goodlin 2009; Hupcey et al 2009). Owing to the significant risk of sudden death at all stages of the disease, there may be a role for 'prospective' management of uncertainty in all patients. This might include

planning for the future and discussion of resuscitation preferences. There is no typical dying trajectory, the unpredictable course of the disease makes the prediction of the terminal phase problematic, the difficulty of recognition of reversible or non-reversible precipitants of deterioration lessens choice and makes access to SPCS more difficult (Horne & Payne 2004; Task Force of the European Society of Cardiology 2005; Gott et al 2007; Goodlin & Cassell 2008; Hupcey et al 2009).

Worsening heart failure may not always be related to underlying pathological deterioration. Reversible causes such as chest infection or anaemia may coexist and be ameliorated, contributing to improved quality of life. The prognosis in patients with heart failure can be considered the least certain of any chronic disease, with at least half of all patients showing no worsening in symptoms prior to death (RCP 2007; National Heart Failure Audit 2009).

People with uncontrollable symptoms of heart failure or who may be dying should benefit from high quality, compassionate care based on good symptom control, psychological support and open communication about disease outcomes (NSF DOH 2000b; GSF 2005). Despite these strategic directives there is still evidence of considerable unmet need for those with heart failure, with only 6% of those dying being referred to palliative care. Most people with heart failure remain, throughout the disease trajectory, in the care of the Cardiology Team (National Heart Failure Audit 2009). Of the 2,669 new patients with a non-cancer diagnosis receiving in-patient palliative care only 9% had a heart failure diagnosis, 239 individuals in total (NCPC 2011); this is a 4% decrease from the previous year's data (NCPC 2011).

Heart failure has a poor prognosis with just under 40% of patients diagnosed with heart failure dying within the first year, thereafter the mortality is less than 10% of those surviving each year (Cowie et al 2000). The mortality is 60% at 5 years, and has been described as being the major cause of mortality and morbidity in 21<sup>st</sup> century Europe (Allender et al 2008). In the context of cancer care, survival rates from heart failure are similar to those from cancer of the

colon, and worse than those from cancer of the breast or prostate (Cowie et al 2000; Stewart et al 2001; NCPC 2006d; ONS 2010).

A prospective review by Ellershaw & Ward (2003) indicates that it is possible to identify a small sub-group of heart failure patients for whom the following factors characterise that they are reaching the end of their lives:

- previous admissions with worsening heart failure
- no identifiable reversible precipitant
- receiving optimum tolerated conventional drugs
- deteriorating renal function
- failure to respond within 2 or 3 days to appropriate changes in diuretic or vasodilator drugs

Despite these end of life predictors, evidence from America indicates that less than 10% of people with heart failure receive palliative care (Pantilat & Steimle 2004). By contrast in the UK, of the 60,000 who die each year from HF only 4% receive any specialist palliative care (Kendall 2004 cited in Pooler et al 2007). Heart failure is described by Hauptman & Havranek (2005) as the 'Cinderella of cardiology' (p850).

### **2.3.3. Dementia**

The prevalence and incidence of dementia increases with age. It is estimated that approximately 700,000 people in the UK have dementia and 100,000 will die each year. This represents 5% of the total population aged 65 and over, rising to 20% of the population aged 80 and over. It is estimated that by 2026 there will be 840,000 people with dementia in the UK, rising to 1.2 million by 2050 with 60,000 deaths each year being directly attributable to dementia (Alzheimer's Disease Society 2010). In Wales the number of people with dementia is currently, at the time of writing, 36,532, with a projected increase of almost a third by 2021 (Dementia UK 2007).

'Dementia' is a generic term describing the symptoms that occur when the brain is affected by certain diseases or conditions. These symptoms are caused by structural and chemical changes in the brain as a result of physical diseases such as Alzheimer's (Dementia UK 2007). This is the most common

cause of dementia, affecting around 465,000 people in the UK. It is a physical disease affecting the brain in which plaques and 'tangles' develop in the structure of the brain, leading to the death of brain cells and a shortage of neuro-transmitter chemicals. It is a progressive debilitating disease, which means that as parts of the brain are damaged the symptoms become more severe often including a decline in memory, reasoning and communication skills, and a gradual loss of skills needed to carry out daily activities.

Dementia is one of the main causes of disability in later life. In a worldwide consensus consultation for the World Health Organisation's *Global Burden of Disease* 2003 report, disability from dementia was accorded a higher weight than that for almost any other condition, with the exception of spinal cord injury and terminal cancer. Older people are likely to have multiple health conditions – chronic physical diseases affecting different organ systems, coexisting with mental and cognitive disorders. Co-existing dementia, however, has a disproportionate impact on capacity for independent living with its global public health significance being underappreciated and misunderstood.

Deaths in which dementia is the primary or contributory cause are often marked by an uncertain trajectory. Cox & Cook (2002) describe mechanisms of dying with dementia. Individuals may die with a medical condition that is not related to the dementia. For example this might include a person with mild dementia, who develops and subsequently dies from cancer. Secondly, people with dementia may die with a complex mix of mental and physical problems where dementia is not the primary cause of death although the conditions interact. Thirdly, people may die from complications arising from end-stage dementia. The most frequent symptoms experienced in the last year of life are cognitive impairment, incontinence, pain, low mood, constipation and anorexia. This symptom profile is similar to those experienced by individuals with advanced cancer but people with dementia experience them for longer (McCarthy et al 1997). Recent national figures indicate that 15% of all deaths are directly attributable to dementia (National End of Life Care Intelligence Network 2010).

In an editorial, Hertogh (2006) suggests that the central problem for this patient group is that dementia is rarely recognised as a terminal condition. There is a higher rate of depression and psychosis earlier on in the illness and reduced levels of understanding. Such unique characteristics of the disease require different methods of planning and delivering of palliative care (NCPC 2006e).

Sampson et al (2006), in a UK retrospective case note audit comparing older people dying with or without dementia, describe significant findings in that those with dementia are less likely to be referred to SPC (9-29%) and are prescribed fewer palliative medications (28-51%). The same study replicated in an American nursing home found dementia patients were burdened by active and intrusive interventions, with 25% being tube fed, 49% having laboratory investigations following venepuncture and 11% being subject to physical restraints. The NCPC (2009a) indicate that questions about when the dying phase has been entered, how symptoms (such as pain) should be assessed and managed when communication is no longer possible with the person, together with decisions about the cessation of, or continuation of treatments, particularly where those involve artificial feeding or hydration, and issues about the place in which the person should be cared for, are all complex and difficult to address in practice.

Early data suggested the median length of survival from diagnosis of dementia to death was eight years and during this time ability and awareness gradually decrease whilst symptom load (for example confusion, incontinence, pain, distress, problems with eating and sleeping) increases (Van der Steen et al 2002). More recent evidence from a population based cohort study (Xie et al 2008) indicate a shorter life expectancy of 4.5 years and therefore advanced care planning and proactive management are more crucial. Thus there is a recommendation for more integration between dementia and end of life care services (NCPC 2009e). There is a clear dichotomy in relation to management, as identified by the NHS Chief Executive David Nicholson (2008):

Dementia is, on the one hand, a long term condition, but it is, on the other hand, an issue in relation to end-of-life care. What we have not done yet is put together a set of pathways that would be applicable in most circumstances. That is one of the things that the strategy [*the National Dementia Strategy*] will have as a priority.

The earlier Regional Study of Care of the Dying found that more patients with dementia experienced pain in the last six months of their life than patients with cancer. They are also less likely than other people to be admitted to hospital or a hospice in the last year of life (McCarthy et al 1997). 2,669 new patients with a non-cancer diagnosis received in-patient palliative care of which the number of dementia patients was recorded at 4%; the authors suggest this may relate to under diagnosis of dementia or the possibility that it may be an underlying condition in a significant number of cases (NCPC MDS 2011:22). In an effort to improve this situation the NICE & SCIE (2007) guidelines recommend that dementia care should incorporate a palliative care approach from the time of diagnosis to death.

The percentage of research papers (since 2002) devoted to these chronic life-threatening disorders at the end of life reveals an ordering of research funding priorities: cancer 23.5%, cardiovascular disease 17.6%, musculoskeletal disorders 6.9%, stroke 3.1% and dementia 1.4% that does not appear to reflect their incidence, morbidity or burden (Dementia UK 2007). These priorities also reflect the clinical picture of SPC in which those with a non-cancer diagnosis are under-represented.

In conclusion, in relation to clinical diagnosis there appears to be a lack of understanding as to who, and when, to refer (Ahmed et al 2004). Recognition of the need for palliative care is a difficult process as the course of many life-threatening illnesses is difficult to predict (GMC 2010). As a consequence it is not considered as an option until very late in the illness trajectory (Ellershaw & Ward 2003), which can result in unmet needs and poor outcomes.

## **2.4 DISEASE TRAJECTORIES**

Causes of death in the UK can be categorised in the following ways:

- 8% as a result of a sudden, unpredicted event,
- 32% as a result of organ failure (most commonly respiratory or heart disease),
- 32% as a result of increasing frailty, dementia and co-morbidities,
- 24% as a consequence of advanced cancer, and
- 4% not categorised

(Gold Standards Framework 2006).

The clinical course of patients with eventually fatal chronic illness seems to follow three trajectories or patterns of care needs (Teno et al 2001; Lunney et al 2002; Lynn & Adamson 2003; Murray et al 2005; Dy & Lynn 2007; Murray & Sheikh 2008). A disease selected from each of these three trajectories has been chosen for comparative exploration in this thesis.

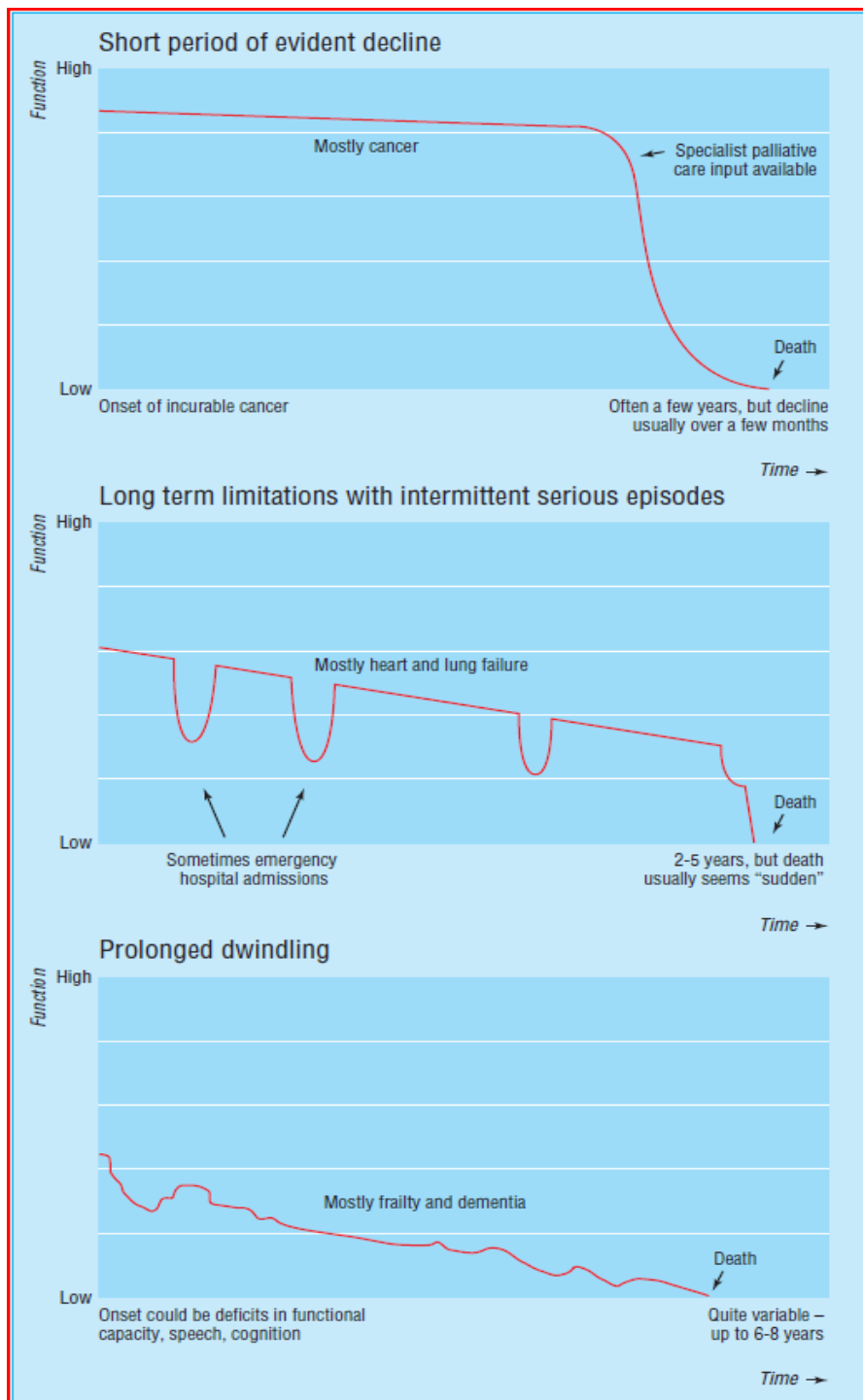
The trajectories outlined by Lynn & Adamson (2003) and Murray et al (2005) (see Figure 1) differ in one major respect, in that Murray and his colleagues attempted to identify a time period for each trajectory. The first trajectory model fits the traditional pattern for cancer and its growing recognition as a chronic illness. It demonstrates a period of active treatment with the potential for remission prior to relapse and a steady slow decline towards inevitable death. The individual during this process becomes progressively weaker and typically this trajectory is of a short duration lasting approximately 6 months. For cancer patients most maintain comfort and functioning for a considerable period. However, once their illness becomes overwhelming their functional status usually declines rapidly in the final weeks and days before death (Weissman 2004). Oncologists caring for individuals with advanced cancer will be the second participant group for this study.

The second trajectory relates to organ failure - lung, heart and kidney most commonly. This trajectory is characterised by deterioration in functional ability accompanied by unpredictable exacerbations of the disease which necessitate acute interventions. The recovery from the acute events may not promote recovery to the pre-existing state, with the outcomes of the acute

events being difficult to predict. This slow downhill trajectory may last anything up to 2 to 3 years. The individual's overall health status is low in the 6-24 months prior to death but cognitive functioning is rarely impaired. In comparison with cancer patients, prediction of death is more difficult until very close to the event (Hallenback 2003). Heart failure is the exemplar of this trajectory being used in the thesis, with cardiologists being the first consultant group studied.

The third trajectory is predominantly associated with dementia and frailty. It often includes people with a number of co-morbidities associated with organ failure or even cancer. This group of individuals suffer from a prolonged period of low function and inevitable decline, which may last for many years. As discussed earlier in the previous section dementia shortens the lives of those who develop the condition (Fitzpatrick et al 2005). Previously the care of this patient group was delivered by care of the elderly services. Currently their care is predominantly undertaken by Old Age Psychiatrists, who make up the third group of participants in this thesis. The ordering of the participants' stories in Chapters five to eight reflect the order in which they were interviewed rather than the order of Murray et al's (2005) disease trajectories





**Figure 1: Murray et al. (2005) Illness trajectories and palliative care. BMJ 330:1008.**

It appears that diagnosis of the dying phase is often more certain for people with cancer, bringing about the ability to determine the future for the patient, their family and professional staff. It may also make it easier to determine the point at which specialist palliative care interventions are appropriate and would offer useful outcomes. The clinical dilemmas in relation to individuals with heart failure or dementia may be related to diagnosing approaching

death, how treatment or access to care decisions should be timed and eliciting which interventions would be helpful (NCPC 2006a; Murray & Sheikh 2008). With non-malignant disease, the tipping point at which really sick becomes dying is clinically and practically difficult to ascertain (Finucane 1999). Models of palliative care would benefit from recognising that the trajectories of different diseases differ and the timing and nature of palliation must reflect this (RCP 2007). A recent DH (2007) review suggests that 29% of people aged over 85 who have a diagnosis of cancer, heart or lung disease are also affected by dementia. This is likely to further complicate understanding of disease trajectories, prognostication and subsequent referral.

## **2.5 PROGNOSTICATION**

In end of life care the significance and intention of establishing a prognosis is threefold. Its clinical importance lies in providing individuals and their carers with information about the future course of their disease and facilitates consequent decision making. Personally it enables patients and families to 'put their affairs in order' and organisationally it acts as a tipping point in supporting access to services, additional resources and benefits (Christakis 1999; Glare et al 2003a; Stevenson et al 2010).

In their systematic review, Ahmed et al (2004) highlighted the double disadvantage experienced by many potential patients who are diagnosed with a life-threatening illness that does not readily enable access to palliative care services. Shah et al (2006) suggested that the provision of palliative care for patients with non-cancer conditions is hindered by the difficulty of predicting when people will die and fear of causing distress by raising end-of-life issues. They compared patients' and professionals' estimations of prognosis, perceptions of the seriousness of the illness and needs for supportive care. In a prospective, comparative cohort study conducted in a teaching hospital and a Marie Curie hospice in London, 20 patients with advanced non-malignant disease (heart failure, chronic obstructive pulmonary disease and renal failure), 20 patients with advanced cancer, and their consultant physicians took part in a feasibility study using clinical vignettes to aid their estimation of prognoses.

The patients were willing and able to estimate their own life expectancy and cancer patients correctly estimated that they had a poorer prognosis than non-cancer patients. Non-cancer patients perceived that they had similar needs for supportive care as cancer patients. Physicians made little distinction in palliative care needs between patients with and without cancer, but tended to make more pessimistic estimates of prognosis in non-cancer patients. Patients appeared able to judge their health status and life expectancy and did not object to questions about end-of-life care. The authors concluded that cancer and non-cancer patients have similar needs for supportive care (Shah et al 2006).

Use of palliative care services beyond cancer is compromised by the difficulty in judging prognosis. Specific prognostic indicators for each of the end of life patient groups, cancer, organ failure and the frail elderly, attempt an estimate of a life expectancy of less than a year and serve as a rough guide in identifying people who may benefit from palliative care. Most studies exploring prognostic scoring consider patients with advanced cancer, although their accuracy and transferability in predicting life expectancy for illnesses other than cancer is now being explored (Fox et al 1999; Glare et al 2003b; Hayden et al 2006). In a systematic review Coventry et al (2005) concluded that current tools were impractical for the assessment of the palliative care needs of older people with non-cancer life threatening diseases and as a consequence they may be overlooked and their palliative care needs not met.

Compared with cancer patients, those with a non-cancer diagnosis are a heterogeneous population with an unpredictable 'up and down' disease pattern which does not fit with most tools that were initially developed to suit the more predictable cancer trajectory.

The difficulties experienced by professionals in recognising dying and predicting survival are well known across all diagnostic groups (Murtagh et al 2004). Evidence indicates that both doctors and nurses are inaccurate in their predictions for their dying patients, generally being over-optimistic. Statistical determinants as to which doctors are more accurate at prognostication were

equivocal. Surgeons were more accurate than doctors in general practice, cancer specialists ranked third, but they performed better than other specialists. There was a slight tendency for more experienced physicians to be better prognosticators. The better the physician knew the patient, the more likely he or she was to optimistically err. Evidence suggested that in practice neutral doctors, having less contact and personal involvement with the patient, may provide more accurate prognoses (Christakis 1999).

Parkes' early study (1972), which concentrated on a homogeneous cancer patient population, identified that doctors were poor at predicting length of life in their terminally ill patients. Almost thirty years later Christakis & Lamont (2000) made similar findings suggesting that oncologists in particular may become so involved in their patients' care that they fail to recognise deterioration in their clinical condition. Parkes' (2000), in a reflective commentary on Christakis & Lamont's work, proposes that clinical predictions would be more reliable if they were based on the use of a scoring system as an adjunct to clinical judgement and intuition. This approach has been confirmed by Gwilliam et al (2011).

Such apparent uniform prognostic inaccuracy may lead to unsatisfactory end-of-life care. Physicians appear well trained in diagnosis and treatment but are less informed about, ignore, and often actively avoid, prognosis. For many reasons they are unwilling to make predictions about a patient's future and act as 'gatekeepers' influencing access to other services (Christakis 1999). This may relate to the requirements for patients receiving hospice care in America to rescind the opportunity for future active interventions. The ideal time for entering a hospice, the researchers say, is about three months before death (Iwashyna & Christakis 1998). Characteristically patients only receive a month of such care. Referral to a hospice or other forms of palliative care is likely to be delayed or not facilitated. Over-optimism may preclude concentration on improving quality of remaining life, delay the use of narcotic drugs and embark on futile therapeutic strategies.

Diagnosing the last hours, days or weeks of an individual's life is essential in order to provide appropriate care (GMC 2010; Gott et al 2011). It is however a complex process dependent both on the patient's diagnosis and the place of care. Vigano et al (2000), in their systematic review of 24 relevant published English language cohort studies, concluded that survival predictors in cancer patients at the end of life are hindered by methodological limitations including accessing representative study cohorts, inappropriate statistical analyses and methods. Despite this they found that performance status, clinical prediction and the presence of cognitive impairment, weight loss, dysphagia, anorexia and dyspnoea appear to be important prognostic factors of survival or imminent death in this population, although they cannot be extrapolated to predict the outcome for an individual patient.

In some countries prognostic indicators are commonly used to identify individuals who may need or benefit from palliative/end of life care. It is possible to classify them as survival curves, performance status indicators, patient signs and symptoms, biochemical profiles, clinical prediction and integrated models combining some of the preceding. None are able to predict with certainty, are characterised by error and only able to provide a best 'guesstimate'. Despite resources being available to support their use in the UK they are not widely considered (Stevinson et al 2010).

Gwilliam et al (2011) in the recent Prognosis in Palliative Care (PiPS) study attempted to develop a novel prognostic indicator tool for use with patients with advanced cancer that is an improvement on the over-optimistic, often unreliable and subjective clinicians' predictions of survival. They created two scoring systems that are able to predict survival times in terms of days, weeks and months and the authors are currently validating their use in practice. Neither scale has proved to be significantly more accurate however than a multi-professional survival estimate.

Clinical estimates and prognostic scoring systems, as discussed, are likely to fail because of their uncertainty in predicting end of life in most non-cancer conditions. A more pragmatic approach is emerging by the suggestion of

using needs-based prognostic coding – including the 'surprise question' to predict main areas of need and support required.



**Figure 2: Needs based prognostic coding.** [GSF in Primary Care Briefing Paper](#) (2006).

The GSF 'surprise' question 'Would you be surprised if this patient were to die in the next 6-12months?' is an intuitive question integrating co-morbidity, social and other factors. The GSF (2006) indicates that if it would not be a surprise, measures might be taken to improve patients' quality of life now and in preparation for the dying stage. Their surprise question can be applied to years, months, weeks, days and trigger the appropriate actions. The aim is to enable the right thing to happen, at the right time and in the right place (GSF 2010). For example, if days are predicted then the Integrated Care Pathway for the dying might be helpful as a guide to care.

More recently they have reframed the question slightly, as some clinicians reported finding it easier to ask themselves 'Would you be surprised if this patient were still alive in 6-12 months?' (Prognostic Indicator Guidance Paper GSF 2006:1). This reframing may confirm evidence of clinicians' difficulty in talking about and diagnosing dying (Christakis 1999). Irrespective of how the question is phrased the responses should predicate appropriate clinical actions. The RCP (2007) support this approach and recommend that

Clinicians should begin with the general identifier that end-of-life should start when it would no longer be a surprise if the patient should die in the next year (p.xi).

In considering the trajectories for non-cancer diagnoses it is suggested that the identification of specific triggers along a disease care pathway could act as a tipping point to promote end of life discussions and initiate palliative care referral. These include the time of diagnosis, commencement or completion of treatment, recurrence or relapse, recognition of incurability and the point at which dying is diagnosed (Cancer Action Team 2007). Although these are triggers suggested for those with a cancer diagnosis, their transferability is

suggested to other diagnostic groups and may have relevance for those with dementia although this lacks acknowledgement of, as explored previously, the difficulties of the 'roller coaster' trajectory associated with organ failure.

Small et al (2010) suggests that the surprise question (GSF 2006) for those with organ failure, particularly COPD and HF, is inappropriate and can deny palliative care for this group of patients by acting as a screening tool. The surprise question being reductionist and narrow in determining who is appropriate for palliative care, its strength however may lie in it being the starting point for discussions related to the changing goals of care for all patient groups.

Models of palliative care offered to the non-cancer population that refute the cancer prognosis-based approach, might facilitate more appropriate and timely referral to SPCS (GSF (DOH) 2005; All Wales Integrated Care Pathway for the End of Life WAG 2006). At a strategic level, as part of the End of Life Care (EoLC) project (DOH 2006), professionals are being encouraged to adopt prognostication as part of clinical care for all people with life-threatening illnesses (GSF (DOH) 2006). They suggest that making a survival prediction may also facilitate discussions regarding SPC referral. The European Association of Palliative Care (EAPC) review of prognostication recommends the establishment of an end of life prognosis for patients both with cancer and with a non-cancer diagnosis, as a means of improving their clinical care in part by facilitating appropriate SPCS referral and the establishing of new models of collaborative working between the different professional specialities (Maltoni et al 2005).

The Northern Ireland Cancer Network (2008) Model for Quality Palliative and End of Life Care states that a number of triggers can prompt the initial identification, assessment and recording of needs. These may include:

- Diagnosis of a progressive or life-limiting (threatening) condition
- Critical events or significant deterioration during the disease trajectory, indicating the need for a 'change of gear' in clinical management
- Significant changes in patient or carer ability to "cope" indicating the need for additional support

- Prognostic indicators
- The surprise question
- Recognition of the last days of life when death is expected.

Their list was adapted from cited work developed by King's College, London (2007) and reinforces the importance of using a myriad of strategies to determine or establish an end of life prognosis.

Montgomery (2006) summarises the difficulties for clinicians in establishing an end of life prognosis as being compromised by 'therapeutic optimism, doubt about the relevance of statistics to the individual patient, a wariness of self-fulfilling prophecies, and the fear of death' (p126). These factors potentially, (either collectively or individually) impact on physicians' referral to SPCS.

If professionals find it difficult to establish (and communicate) an end of life prognosis with confidence, they are less likely to make onward referrals to appropriate services. The combination of these two barriers (prognosis and referral) will have a serious consequence on the planning and co-ordination of care. They will also act as a barrier in ascertaining and discussing patient (and family) end of life care choices (Addicott & Ashton 2010; Gott et al 2011).

## **2.6 PATIENT PERSPECTIVES**

Research has identified a number of factors related to the patient that mitigate against referral to SPCS, these may include the economically disadvantaged living in deprived neighbourhoods, in either urban or rural areas, individuals with mental health problems, older people, those with physical and mental disabilities and people from black and ethnic minority groups. The influences of the family, the media, culture and religiosity also all appear to impact (Koffman et al 2001).

In Wales the impact of geographical and cultural factors are acknowledged and recognised (WAG 2006) specifically in relation to service planning and delivery:

The unique and varied characteristics of Wales – the complex pattern of settlement, ranging from inner cities



to very sparsely populated areas, and the mix of languages and cultures - pose a difficult challenge in ensuring equitable access to services that meet the diverse needs of patients in a wide range of settings (Cancer Services Co-ordinating Group, WAG 2006).

A number of studies confirm inequities in access to SPCS which are apparent for the elderly, minority ethnic groups and those within the rural population (Karim et al 2000; Firth 2001; Bestall et al 2004; Audit Scotland 2008; Rolls et al 2010). This links with geographical evidence that some people are not referred to these services because they are socially excluded, for example by living in areas of social deprivation, being homeless or in institutional care (Addington-Hall et al 1998b; Katz et al 1999; Koffman & Camps 2004). There is evidence in the UK that although palliative care services for cancer are well developed the chances of dying in a hospice lessens with increasing age (Lock & Higginson 2005).

Palliative care services are used mainly by people with cancer (NCPC 2006a). Cancer incidence and mortality is relatively lower in most minority ethnic groups (Aspinall & Jacobson 2004; Evans et al 2011). Wider studies show that access to services for minority ethnic groups can be limited particularly by the 'gate-keeping' behaviour of GPs (Smaje & Field 1995; Koffman & Higginson, 2001). Questions related to access to care for ethnic minority populations in the NCPC minimum dataset survey (2008 to 2009) identified that it had improved, suggesting that the percentage of non-white patients is increasing. This ranged from 11.4% in bereavement support up to over a third of non white patients receiving day care (34.8%). Recent data from 2010 indicates that palliative care services were only able to ethnically categorise their patients in 88% of cases. On average 5% of inpatients categorised themselves as non-white: 2% black (African, Caribbean or other), 1% Indian, Pakistani or Bangladeshi, 0% mixed race with 2% of other ethnicity including Chinese (NCPC 2011). This reflected an increase of 2% since 2006. There is also evidence of reluctance by some family members of ethnic minority groups to access external support in relation to palliative care. They believe it

is an important family responsibility to be the principal carers for those who are dying (Ahmed at 2004; NCPC 2006c).

Evans et al's (2011) recent interpretative systematic review of access to EoLC for minority ethnic groups identified six themes from the literature. These were structural inequality, inequality associated with diagnosis, referral reluctance, place of care and death, communication and awareness issues and lack of cultural competence in care. Except for the last theme, other themes link with the experience of most patients at the end of life (DH 2011b).

The age profile of patients receiving SPC suggest that it is statistically more likely for those between the ages 45-74 years than for those over the age of 75 years (WHO 2004b; ONS 2004; Help the Aged 2005). Burt & Raine (2006) undertook a systematic review to examine the effect of age on referral to SPCS; and found some evidence that cancer patients over 65 years were less likely to be referred. The outcomes from this review were diluted by the methodological inaccuracies reported in some of the studies. It is possible however, that younger patients, may have more complex needs necessitating specialist interventions (Grande et al 2002).

The media portrayal of palliative care is generally associated with younger people, dying out of time, following a long battle with cancer. Examples of this are the recent death of Steve Jobs from recurrent pancreatic cancer and Jade Goody dying from advanced, mis-diagnosed cervical cancer. This may influence patient and family attitudes to and perceptions of palliative care. Only recently have deaths from conditions other than cancer achieved a higher media profile as discussed in the introduction to this chapter.

The recent NCPC Minimum Data Sets (2011) described the age and gender profile for new patients receiving palliative care in different settings.

- The inpatient profile was as follows: 31% of new patients were under 65
- 12% of new patients were over 84
- 13% of the older age group were women and 12% male
- Fewer than 1% were under the age of 25.

The specialist hospital palliative care support team profile being:

- 26% of new patients were under 65.
- 27% of those under 65 were women, 25% were men.
- 18% of new patients were over 84.
- Fewer than 1% were between the ages of 16-24.

Thus the national profile identified that the majority of patients were in the age group between 65 and 84, which perhaps links with age-related cancer incidence and changes in population demographics. These figures do not reflect the more global evidence of Burt & Raines' (2006) systematic review. The MDS (NCPC 2011) do not ascertain the presence of co-morbidities, mental health and learning difficulties, educational level or household and socio-economic profiles in their analysis of palliative care service activity. The above factors were, however, all included in an earlier American study. Chen et al (2003) compared hospice and hospital patients' demographic, clinical, and other characteristics. Multivariate statistical analysis was conducted to identify variables associated with hospice care referral decisions. Patients receiving hospice care were:

- significantly older (average age 69 vs 65 years,  $P = .009$ )
- less educated (average 11.9 vs 12.9 years,  $P = .031$ )
- from larger households (average 1.66 vs 1.16 persons,  $P = .019$ )
- presenting with more co-morbidities (1.30 vs 0.93,  $P = .035$ )
- assessed with worse activities of daily living scores (7.01 vs 6.23,  $P = .030$ ) than hospital patients.

There was lack of clarity made as to the variables associated with a cancer or non-cancer diagnosis and their impact on referral.

People with dementia, learning difficulties, mental health and sensory disabilities also appear to have reduced access to these services (Olivière & Monroe 2004). A census of primary care teams in England rated the groups with most unmet needs in terms of EoLC as patients with conditions other than cancer, people with mental health problems or dementia and older people (NAO 2008).

Other variables relating to the patient that appear to impact on referral include their diagnosis (see earlier) and family influences (Addington-Hall & Higginson

2001; NICE 2004). There is some indication that patients with conditions other than cancer may be reluctant to access palliative care seeing it as synonymous with cancer and a precursor to impending death. Ahmed et al's systematic review (2004) also identified some reluctance on the part of patients and families for a palliative care referral based on misunderstandings and its association with impending death. This may also influence professionals' referral practices.

Rosenwax & McNamara's (2006) retrospective quantitative cohort study described the characteristics of people from Western Australia who did or did not receive SPC during their last year of life. Barriers to referral related to geographical remoteness and rurality, being a member of an indigenous ethnic group or having a non-cancer diagnosis. Older people, those who were single, widowed and divorced were also less likely to have received palliative care. Individuals with a non-cancer diagnosis, particularly those with a diagnosis of COPD and Alzheimer's are less well represented, although it is possible that there was a degree of under-reporting for some patient groups. This study elicited data at a population level to inform service developments but the individual information gleaned supports earlier evidence of service inequality.

Patient and family reluctance for referral to SPCS is often related to their lack of understanding of their disease and their sometimes unrealistic expectations of treatment and its outcomes. Both dementia and heart failure are terminal conditions but unlike cancer are not viewed as such by the general public and many patients and carers. This is also linked to the death denying culture in society which suggests that death can be 'held at bay' by technological advances in medical and health care (NIE 2010).

Brett & Jersild (2003) considered that inappropriate treatment near the end of life was often the result of a conflict between religious convictions and clinical judgement. Using evidence published in the Archives of Internal Medicine they indicate that, not infrequently, Christian patients and families provide religious justifications for an insistence on aggressive medical care near the

end of life. Four commonly invoked reasons are, hope for a miracle, refusal to give up based on faith in God's will, a conviction that every moment of life is a gift from God and is worth preserving at any cost and belief that suffering can have redemptive value. This is unlikely to be an exclusively Christian perspective although there is only limited evidence in relation to other faith groups.

Conversely other research has shown that many Christians understand and accept the withdrawal or withholding of therapy at the end of life (Pauls & Hutchinson 2002) and the Jewish legal perspective supports this approach for dying patients. Jewish law requires the provision of palliative care to the patient and family as part of the moral imperative to relieve suffering and promote comfort (McIntyre 2009). The same approach is supported for Muslim patients where certainty of imminent death is assured and by most Buddhists who believe there is no moral obligation to preserve life at all costs (Bülow 2010).

There is a clear link between these faith perspectives, the WHO philosophy of palliative care (WHO 2011) and an expectation that establishing an end of life prognosis enables access to services and guides subsequent interventions.

## **2.7 PHYSICIAN PERSPECTIVES**

Health service variations, knowledge of, and attitudes towards, SPCS and the multidisciplinary team's experience of palliative care also contribute to referral decisions (Farquar et al 2002; O'Leary & Tiernan 2008). Knapp et al (2009) cite a number of studies where there is a significant difference between hospital based physicians' and general practitioners' decisions to make a referral to palliative care with hospital physicians being more reluctant to refer (Dharmasena & Forbes 2001). In a recent English qualitative study exploring transitions to a palliative care approach in the acute hospital setting, Gott et al (2011) identified that barriers were related to prognosis being rarely discussed with patients and lack of consensus within the clinical team about the transition to palliative care which was exemplified by professional hierarchical decision making and poor communication. Attitudes to and perceptions of

palliative care did not appear to influence Gott's participants, possibly the focus group approach to data collection may have hindered more personal disclosures.

It is suggested that non-clinical factors together with external and organisational structures influence how health care professionals establish that a person is nearing the end of their life and consider referral to SPCS (Lynn & Adamson 2003). It may be that the triggers initiating referral to SPCS occur independently of making an explicit end of life prognosis and that referral based on clinical judgement and experience implicitly acknowledges that end of life is imminent. For example a significant number of the oncologists in Johnson et al's study (2008) agreed that all patients with advanced cancer irrespective of specific need should be referred to SPCS. Therefore their use of specialist services was largely indiscriminate and routine and not based on the establishing of an end of life prognosis. In relation to individual professionals' referral practices Johnson et al (2008) suggest other significant indicators in support of making a referral might include the oncologists being female and also being a specialist practitioner for more than 10 years.

Referrals to SPCS mostly require a medical referral. Physicians rightly believe that decisions to refer are their responsibility. As a consequence it is likely that all doctors sometimes act as 'gatekeepers' in supporting or denying access. By not offering it as a therapeutic option they are influencing patient treatment choices in relation to their options for care. It is suggested that doctors' positive or negative perceptions about palliative care may contribute to their decisions to refer or not refer and therefore influences access to specialist services (Johnson & Slaninka 1999; Friedman et al 2002; Johnson et al 2008). Many doctors view referral to palliative care as being synonymous with predicting end of life and death and this attitude may therefore influence their referral decisions (Christakis 1999; Cherny & Catane 2003). It is clear that in the acute hospital situation there is limited opportunity for junior medical and nursing staff to input into decision-making related to the

transition to palliative care, it is primarily seen as the consultant's responsibility, however onerous (Gott et al 2011).

Ward et al (2009) in a national Australian web-based survey sought to elicit the views of oncologists towards collaboration with SPC. Most oncologists who responded demonstrated a more collaborative approach by accessing palliative care for 87.4% of their patients. Timing of referral for 75% of the respondents was not an issue, neither was the feeling of professional failure if a referral was made (for 97%). Reasons for non-referral were identified as SPC services not taking a referral if the patient is receiving anti-cancer treatment, not having adequate resources to take the referral and the physicians' belief that the patient and family would be reluctant for palliative care involvement. Highlighting the response rate of 30%, Ward and her team suggest that there is a potential response bias with those most interested and holding the strongest views being the most likely to have completed the survey. In comparison, in earlier but similar EU and US studies Feeg & Elebiary (2005) identified that oncologists only accessed palliative care services for 35.1% of their patients.

In both Ward et al (2009) and Feeg & Elebiary's (2005) studies the oncologists preferred service model was for concurrent rather than sequential care. This is consistent with UK studies where GP's preferences are for shared care approaches (GSF 2005) and supported by strategic guidelines proposed for end of life care for those with a non cancer diagnosis (DOH 2008).

A number of studies explore perceptions of palliative care and heart failure and how these impact on referral practices. Hanratty et al's (2002) qualitative focus group study of primary and secondary care physicians in Northern England identified organisational barriers, prognostication difficulties, together with conflicting medical roles and responsibilities as all impacting on referral. They highlighted the inability of palliative care doctors to deal with the complexity of heart failure and the unwillingness of cardiologists to refer their patients to SPC.

In a later, but related, study Hanratty et al (2006), using heart failure as the exemplar, explored different specialist consultants' views on the care of the dying. All had some role in end of life care. The participants demonstrated an understanding of the concept of palliative care but had difficulty in appreciating its benefit beyond cancer. Their perceptions related to it being about managing dying, the cardiologists stating that they did this too late, finding it difficult to switch from 'rescue to comfort' (p 495), in letting go and dealing with the messages that it might give the patient. The elderly care physicians appeared more confident, stating that they manage it themselves. All participants believed that palliative care was more the province of nurses in that it was straightforward and did not require the technical knowledge and specialist expertise that characterises the role of doctors. They also acknowledged that palliative care was important and more than a service, that it was a philosophy or a place of care. For most their clinical dilemma related to establishing the appropriate timing for its use.

The researchers commenting on their study stated that the participants were 'typical' consultants (without clarifying what this meant). The focus groups were undertaken as single speciality groups and as such there was minimal challenge within the groups, but on reflection mixed groups might have focussed and extended the responses. It appeared that the consultants had knowledge but

for many doctors, the attitudes, beliefs and self-perceptions that underpin professional practice may be potent barriers to holistic [palliative] care (Hanratty et al 2006:497).

The medical model of care, focussed on empirics and interventions associated with curative intent, are inculcated as part of physicians' training. Subsequent professional development suggests care of the dying is a difficult task for physicians. Their role encompasses both technical and human skills related to establishing and communicating a prognosis, symptom control and the support of patients and relatives. Educational strategies with emphasis on these aspects may be helpful and as shown by many authors are teachable (Charlton 1993a; Hillier & Wee 2001; Field & Wee 2002). Although included



in the undergraduate curriculum many newly qualified doctors feel ill prepared (Herzler et al 2000) and experience a 'tension between emotional concern and professional detachment' (Kelly & Nisker 2010:421). For more experienced clinicians, lack of resources and the need for additional training are often cited as barriers in providing palliative care to non-cancer patient populations (Field & Addington-Hall 1999; Addington-Hall et al 2001; Hillier & Wee 2001).

Hardy et al (2008) in a survey of palliative care professionals in Australia, asked them to rank 42 pre-determined barriers (derived by a focus group), that had been identified as militating against the provision of optimal palliative care. The most significant barrier identified was related to their lack of knowledge in relation to how to care for the dying. This was linked to them viewing death as a professional failure and thus they tried to avoid it. They also cited resource issues, with limited availability and access to palliative care services which appeared linked to society giving a low priority to care of the dying. This supports earlier American studies that identified limited opportunities for training in palliative care, reluctance of physicians to refer, believing hospice care was synonymous with death, unfamiliarity with the range of services offered together with communication and prognostication difficulties (Zabroff et al 2004; Feeg & Elebiary 2005).

Boyd & Murray (2010) suggest the existence of 'prognostic paralysis' as being one of the barriers to providing an effective service model of palliative care for people with heart failure. This paralysis was reinforced by difficulties in recognising end of life due to prognostic uncertainty, managing co-morbidities and the 'roller coaster' illness trajectory which supports reluctance to discuss end of life issues (all discussed earlier in this chapter). In addition, factors identified include professional lack of knowledge and understanding of what palliative care is able to offer and that palliation is not perceived as a care priority, with medical and device therapy being perceived as more urgent (Hupcey et al 2009).

An almost universal lack of understanding of palliative care exists, many doctors believing that it is a method of service delivery rather than the reality of it being a philosophy of care providing an 'umbrella of services' (Kendall cited in Pooler et al 2007). Their perception that it is pre-death care, that services will be overwhelmed by extension to non-cancer patient populations (Field & Copp 1999; Murray et al 2005) and that patients and families believe that heart failure 'is a benign condition even in the later stages' (Hermani & Letizia 2008:101), all contribute to under use of services.

The bland assumption that palliative care is a better option in all clinical situations is inappropriate, in heart failure there would be benefit in the shared approach of providing optimal physiological support as in improving oxygenation and the use of diuretics together with pain relief and psychological support. This is demonstrated by some authors who believe that as cardiologists they are providing key elements of palliative care as part of their practice (Hupcey et al 2009), whilst others advocate a professional shift to:

a paradigm of blending active and palliative care [which] allows clinicians to succeed in providing excellent patient care (Zambrowski, 2006:572).

Hauptman & Havranek (2005) describe a heart failure care approach which supports integration between conventional and palliative care. This shared therapeutic approach may also be applicable in old age care, specifically dementia, where the management of the mental health aspects is undertaken by old age psychiatrists and the concurrent physical symptoms by the palliative care team (DH 2009b, 2010b; NCPC 2009e).

Workload factors impact on clinical decision making and referral. Clark & Cleland (2005) state that there are 'not enough cardiologists to serve the population, and certainly no heart failure cardiologists to support a demanding new role' (p 849). Resource inequity is a barrier for this patient group. These workload factors are supported albeit less explicitly by old age psychiatrists in relation to balancing care for people with dementia, those with suicidal ideation and acute episodes of mental ill health (WG 2010).

End of life care pathways were developed for professionals to guide care at the end of life by improving decision making, communication and care delivery (Ellershaw et al 1997; Fowell et al 2002; 2003; Ellershaw 2007). The Liverpool and All Wales Care Pathways evolved to support care in the dying phase of palliation (especially in secondary care). Their aim is to improve the deficiencies in symptom control, communication and basic care identified by Mills et al's (1994) observational study of dying in acute hospitals and to promote cost effective care by supporting appropriate patient management such as 'streamlined' prescribing and reducing inappropriate interventions (Ellershaw et al 2001).

Dainty & Leung (2008) describe a small scale study that used the Liverpool Care Pathway (LCP) for the end of life to evaluate the standard of palliative care in a patient cohort of elderly people with differing end-stage diseases. The outcome supports the suggestion that palliative care offered to elderly patients dying from non-malignant conditions requires improvement but the use of LCP appeared to raise awareness and provided a valuable resource in enabling clinicians to 'work smarter' (p330).

The recent Cochrane review of end-of-life care pathways for improving outcomes in caring for the dying (Chan & Webster 2010; updated 2011) attempted to determine whether their use was beneficial or burdensome for dying patients and their carers. They were unable, on current evidence, to recommend their use as there have been no robust evaluations undertaken demonstrating their effectiveness. Anecdotal clinical evidence however appears to suggest they have improved care at the end of life, in particular related to symptom control, communicating that death was imminent and supporting preferred place of care (Neate 2011 – personal communication).

The heart failure framework for implementation (NICE 2010) identifies barriers to, and specific issues from, the professional perspective related to heart failure patients' access to SPC. The issues identified clearly link with the practice of both oncologists and old age psychiatrists:

- The medical model of care.

- Prognostic uncertainty and implied professional failure of not being able to manage the patient's situation.
- Clinical reluctance grounded in fear especially of upsetting patients and carers.
- Change in goals of care.
- Lack of open dialogue related to needs and preferences.
- Patients and carers having little insight related to the implications and significance of the diagnosis of heart failure.

The last point is the only issue not to echo the experiences of patients and carers with cancer and dementia, as both of these diagnoses carry an implicit and ever present fear of death from the outset (Cancer Research UK 2010b). An earlier qualitative focus group and individual interview study undertaken in Northern Ireland by Spence et al (2009) identified identical barriers being present in the delivery of palliative care to the patient group with Chronic Obstructive Pulmonary Disease (COPD).

Chugani et al (2010) identified, by the use of focus groups and personal interviews, the barriers to accessing SPCS for non-cancer patients in Spain after eliciting the views of patients, carers and professionals. The use of prescribed topic discussion cards may have influenced the responses but the following emerged as professional opinions: lack of clarity about prognosis and the hegemony of the curative approach whereby professionals are trained for curing not caring which have been explored earlier in the literature review. An additional barrier, the desire to cheat death and avoid using certain words associated with impending death, links with the medical model of care and the death denying nature of contemporary society also considered earlier in the chapter.

Although caring for patients who die is an intrinsic part of being a physician, health care providers work in a medical culture where death is often viewed as a physician's failure (Lowry 1997; Meier et al 2001). Physicians' professional and personal experiences of death and dying and the impact on their use of palliative care services appears under acknowledged. Lowry (1997) in considering doctors' fears suggests that caring for dying patients forces physicians to confront their own mortality and personal experiences with

death, dying, and life-threatening illness. There is evidence that professionals with prolonged exposure to patients who are dying from a life-threatening illness, such as cancer, or to those who die from an acute precipitate event, such as cardiologists, are subject to a range of stresses that may lead to both burnout and compassion fatigue (Lyckholm 2001; Jackson et al 2008; Kearney et al 2009).

Kearney et al (2009) describe burnout as resulting from 'stresses that arise from the clinician's interaction with the work environment', whereas 'compassion fatigue evolves specifically from the relationship between the clinician and the patient' (p1156). The dynamics of hope and hopelessness in professionals may also be important (Sullivan 2003).

Over twenty years ago Whippen & Canellos (1991) explored burnout in oncologists and found that 56% of respondents reported frustration and a sense of personal failure in their work, concluding that coping with the challenges of providing end-of-life care was the single most important qualitative factor related to their burnout. Their experiences were reported early in the development of palliative care services and do not resonate with a more recent New Zealand study (of a wider physician cohort) that identifies burnout as being present only in a minority of consultants, this was predominantly related to organisational and workload factors impacting on job satisfaction. There was no difference in the consultants' clinical speciality (Surgenor et al 2009). This links with the tensions described in the introduction to the thesis between the macro, meso and micro levels of health care (Pilgrim & Rogers 1999). However, Sturgenor and colleagues reported an unexpected proportion of consultants experiencing robust emotional well-being and healthy work engagement.

Jackson et al (2008), in a multi method study conducted over 2 years, sought to understand the emotionally powerful experiences of white physicians in caring for dying patients. During the interviews for the study physicians recalled and acknowledged powerful experiences with death during all stages of their careers. Their experiences of patient deaths generally fit into one of

three types: 'good', 'overtreated', or 'shocking and unexpected' (p. 648). Physicians described having to learn, through experience, how to care for and cope with dying patients. Many reported changes in their clinical behaviour and career paths as a result, with emotional reactions to a patients' death appearing to affect both clinical care and their personal lives.

Meier et al (2001:3007) identified certain clinical situations that predispose physicians to emotions that increase the risk of 'overengagement' or 'underengagement'. Examples may be both internal (personal) and external (contextual related to the patient, their illness and the clinical situation). Internal factors include the patient being similar to an important person in the physician's life, or having a seriously ill family member, being recently bereaved, or having an unresolved loss. External factors relate to a long-standing and close patient-physician relationship, ambiguity and uncertainty about prognosis and the shifting goals of care. These factors appear relevant to all three specialist professional groups participating in this thesis.

The methodological approach adopted by both Meier et al (2001) and Jackson et al (2008) in exploring physicians' reflections on 'critical incidents', or their clinical experiences, proved particularly useful in understanding important interactions with patients and influenced future care. This links with the methodological approach employed in this thesis.

Physicians' religious faith and ethnicity and its relationship with decision making at the end of life appears poorly represented in the literature. Christakis (1999) observed physicians with deep religious beliefs avoiding making a prognosis, describing it as 'playing God' suggesting an omniscience that they find uncomfortable. He also acknowledged that doctors historically rarely discuss their own religious beliefs. Wenger & Carmel (2004) in a survey of American Jewish physicians' religiosity identified it as having a major effect on the way their patients die, specifically on the management of pain. Those who were very religious were less likely to withdraw life prolonging interventions or prescribe appropriate analgesia if there was a perceived risk of it hastening death. Moderately religious or secular

physicians were more comfortable with supporting palliative (rather than active) interventions at the end of life.

This was supported by Seale (2010) in a large postal survey of multi-faith and ethnically diverse doctors working in the UK. He examined religiosity and ethnicity and its impact on end of life decision making and concluded that a doctor's ethnicity was irrelevant in their making of controversial decisions. However, doctors who described themselves as non-religious were more likely to initiate discussions and make decisions with patients (perceived as having capacity) regarding end of life care preferences. The decisions made were related to ceasing aggressive interventions and not prolonging life and are consistent with literature related to end of life decisions in intensive care (Prendegast 2001; Bülow et al 2008).

There is an assumption at strategic and organisational level that referral to palliative care is a good and desirable thing although there is little evidence to support this perspective. At the operational practitioner level many specialist doctors genuinely believe that they are the best people to keep the diseased system of interest working to capacity, which keeps symptoms under control and the patient comfortable. It appears that for many they see palliative care only being useful for psychological care or in accessing specific resources.

## **2.8 CONCLUSION**

This chapter started with an account of the historical evolution of palliative care services from its initial cancer-centric focus; it discussed the impact and influence of political strategies and agendas that may be compromised in implementation by the current economic constraints. The clinical factors associated with a cancer and non-cancer diagnosis were explored focussing on the difficulty in identifying the tipping point when referral to palliative care services might be indicated. Patient and physician perspectives were explored in attempting to identify factors that acted as barriers or enablers in supporting decision making related to SPC referral.

What became clear from the literature was:

Referrals are often made late, when patients have multiple problems and significant distress. Clinicians must recognise that end-of-life care does not mean that someone is going to die imminently but that [the] approach to their care should change (RCP 2007:11).

Linking with the aim and focus of this thesis the RCP (2007) and GMC (2010) suggest that the early identification of clinical triggers ensures timely, effective and proper care is provided. This may require palliative care referrals to be initiated early and appropriately or that the goals of care provided by specialist physicians reflect the palliative and end of life care needs of their patient group.

Moving beyond the structural context of specialist palliative care the next chapter will explore the theoretical contexts of clinical thinking and knowing considering how they might influence referral decision making.



## **CHAPTER 3 - THEORETICAL CONTEXT: CLINICAL THINKING AND KNOWING IN PRACTICE**

**As we know, there are known knowns. There are things we know we know. We also know, there are known unknowns. That is to say, we know there are some things we do not know. But there are also unknown unknowns, the ones we don't know we don't know.**

**(Donald Rumsfeld, US Department of Defense news briefing, 12 February 2002).**

### **3.1 INTRODUCTION**

The chapter will explore the nature of professional practice. It creates the theoretical foundation on which we might build an understanding of the knowledge bases and decision making of medical consultants in clinical practice, specifically in relation to palliative care referral. This prepares the way for the research approach of IPA (see Chapter 4), its design and methods supporting the exploration and development of individual, and a shared understanding of the consultants' experience.

The key concepts which guided the implementation of the study were IPA's requirements to support rich description of the individual experience, the double hermeneutic interpretative process that supported the participants and my understanding of their particular experience. The phenomenological perspective although systematic involved a particular way of creative and imaginative thinking that was present throughout the research. Specifically the phenomenological concept of the lifeworld as outlined by Ashworth (2003) deepened and enhanced understanding. It influenced my thinking by encouraging me to think about the layers of analysis in my participants' stories by interrogating their understandings. This stance supported acceptance of their stories at face value, encouraged a reflective and speculative approach or a combination of both approaches. Thus it gave me the freedom to push the analysis, which was helpful when revisiting the data at the time of writing up. It was this activity that encouraged me to think about the concepts of habitus, clinical mindlines and led me to consider more in depth concentration on language and metaphor.

It is acknowledged that it is not possible to address the totality of the epistemology of practice in one chapter. It is hoped that what is presented will support the reader to locate the thesis by presenting an overview of the key philosophical tenets as justification and underpinning the theoretical context of the thesis. The theoretical foundation has been derived from selected phenomenological, psychological, linguistic, philosophical and professional literature and appears to have relevance for the consultants' professional practice. The concepts outlined, explored and developed in this chapter also act as a framework for situating the findings in Part 3, the discussion section.

This chapter also provides a scene setting and contextualising framework that positions the thesis within the contemporary pluralistic health and social care arena. It will briefly consider medical practices and the role of the consultant before exploring in greater depth the consultants' life-world of practice, ways of knowing, how they use knowledge in practice and demonstrate judgement based approaches in relation to referral decision making.

## **3.2 CONTEMPORARY MEDICAL PRACTICE - SETTING THE SCENE**

### **3.2.1 Introduction**

Medicine in the 21<sup>st</sup> century is rapidly developing. Its knowledge base is evolving as a consequence of scientific and technological advances; the structure of service delivery is changing as a result of national strategies, organisational reconfiguration and resourcing complexities and priorities. Individual practice is becoming increasingly dependent on evidence based outcomes, patient involvement and professional requirements for continuing professional development and appraisal. Despite these changes some medical ideas and practices remain faithful to historical antecedents such as the primacy accorded to scientific knowledge.

### **3.2.2 The epistemology of practice**

In the introduction to their report for the UK DOH *Developing the Attributes of Medical Professional Judgement and Competence* (1999) Eraut & duBoulay acknowledge that the contemporary role of the doctor is multifaceted and complex:

not only are extensive skills and knowledge expected within the doctor's area of specialism, but also high levels of communicative ability, ethical understanding and responsibility, teamworking capability and organisational ability (p7).

Their review tried to elicit the nature of medical competence and judgement prior to identifying the role of postgraduate and continuing medical education in its development. It is the former that is relevant to this thesis and is reflected in many of the participant interviews.

Dreyfus & Dreyfus (1980) in their work with airline pilots identified five stages of competence. They posit that in the acquisition and development of a skill a student passes through five levels of proficiency: novice, advanced beginner, competent, proficient, and expert (Dreyfus & Dreyfus 1986). Further refined by Schon (1987) who suggested a model of professional knowledge which is characterized by four essential components that legitimise it, in that it is 'specialized, firmly bounded, scientific and standardized' (p23). This model appears context dependent and informed by the medicalised view of healthcare in the 1980's. It ignores the importance of experience and unique individual situations which many doctors believe is the essence of their practice.

Eraut (1994) in further attempting to articulate an epistemology of practice describes four distinct but interconnected elements of professional practice that echo elements in the medical consultants' role and the clinical experiences they describe in this thesis. These experiences link with other philosophical and theoretical perspectives outlined later in this chapter.

The first element of professional practice (Eraut 1994) involves assessing clients and or situations, sometimes briefly, sometimes involving a long process of investigation and consultation. In this thesis it relates to achieving a diagnosis and considering active versus passive interventions, identifying which patients might benefit from SPC - this relates to ways of knowing and knowledge. This is closely linked to the second element of decision making in deciding what, if any, action to take both immediately and over a longer period

(either on one's own or as a leader or member of a team). Clinical management in each of the clinical specialties and end of life care involves a progression from small to large decisions. Thirdly, clinical judgement, where past experience and intuition identifies an agreed plan of care which is modified, reassessed and reconfigured when necessary. The final element relates to the metacognitive monitoring of oneself, our patients and their clinical journey and any contextual factors impacting. This sometimes involves learning through reflection on the experience at the time and retrospectively (Eraut 1994).

Eraut's final element of the epistemology of practice links back to the work of Schon (1987, 1991) in acknowledging the value of reflection in which the importance of tacit knowledge in transforming knowing in practice to knowledge for practice is apparent. Eraut's (1997a) later modes of cognition (see below), linking theory with practice appears to be largely derived from the Dreyfus Model of Skill Acquisition (1980) in articulating the knowledge, skill and ethos embedded in practice.

**Table 2: Theoretical and Practical Knowledge (Eraut (2007)).**

Type of Process	Mode of Cognition		
	Instant/Reflex	Rapid/Intuitive	Deliberative/Analytic
Assessment of the situation	Pattern recognition	Rapid interpretation	Prolonged diagnosis. Review with discussion and/or analysis
Decision-making	Instant response	Intuitive	Deliberative with some analysis or discussion
Care Planning	Routinised action	Routines punctuated by rapid decisions	Planned actions with periodic progress reviews

Meta-cognition	Situational Awareness	Implicit monitoring. Short, reactive reflections	Conscious monitoring of thought and activity. Reflection for learning
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Eraut (2007b) acknowledges the impact of the contexts in which the practice takes place and this is akin to the concept of the life-world. He describes the characteristics of 'professional' as being the human and physical environment, relationships, patterns and conditions of work, culture, discourses, knowledge, learning opportunities and agency. This, according to Montgomery (2006), also links with the concept of 'habitus' whereby 'physical symptoms are read narratively, contextually and interpreted in cultural systems' (p13).

### 3.3 THE LIFE-WORLD OF PRACTICE

The epistemology specific to a life-world approach emerged from the phenomenological philosophy of Husserl and Merleau-Ponty together with the interpretative activity supported by Heidegger and Gadamer. Their common epistemological understandings, rather than their differences, support the exploration in this thesis. Their mutual understanding is that life is visible in experience and that their shared philosophical traditions seek patterns and connections of meanings related to shared experiences as well as individual experience. This builds on the earlier rationale for using IPA as the research approach as it supports the integration of descriptive and interpretative elements in an attempt to achieve a deeper understanding of the consultants' individual and shared experiences.

The life-world, Husserl's 'Lebenswelt', is one of the foundations of existential phenomenological thought and refers to an essential structure fundamental to human experience. The life-world can be described as the world that is individually lived and experienced. It is made up of our internal experience of our self, body, senses and relationships and the connection with the external world and how that impacts on our experiences. A core principle of the life-world, in relation to research approaches, supports giving value to

participants' experiences and the acceptance of these as 'evidence', again linking to IPA.

From an interpretative perspective Heidegger does not use the term 'life-world', instead he describes the concept of being-in the-world. For him this implies an enduring reciprocity between human existence and the world. 'Being' however is more elemental than human awareness and knowledge (Husserl 1970; Valle & Halling 1989; Heidegger 1995; Todres 2007). The idea behind the life-world is that it reframes experience by focussing on the individual's lived, current situation within the context of their social world rather than focussing on an internal introspection. This was described by the metaphysical poet John Donne (1572-1631) in *Devotions upon Emergent Occasions* as 'No man is an island entire of itself; every man is a piece of the continent, a part of the main' supported almost four centuries later by the phenomenological theorist Merleau-Ponty 'man is in the world, and only in the world does he know himself' (1962:xi). This supports the perspective of considering the relationship between the individual and the world, the unique and the universal (Merleau-Ponty 1962, 1995).

The individual's life-world is pre-reflective. It is a sensing occurring independent of thought or language. It links to the ideas of tacit knowing and intuition that something is known inside that is a bodily sense or a felt meaning. An example being when clinicians often describe having a 'gut feeling' that something is wrong with their patients. Gadamer (1997) supports the idea that the life-world is tacit but also that we live in the world as 'historical creatures' - that our past experiences as human beings are the foundations that structure subsequent experiences. Thus the life-world is a world of multiple possible meanings, it is never completely understood, language and human understandings are inadequate tools to explain it and there is always more (Gendlin 1997).

For Merleau-Ponty the connection between past and present experiences encourages new and potentially synergistic understanding. This idea supports the temporal aspect of the life-world in which the consultants' past

and anticipated experiences make for meaning which influences their understanding and their practice. In this thesis it specifically focuses on how their experiences influence their perceptions of palliative care and their decisions related to palliative care referral. Meaning-making is never static. It evolves, is contextual and unbounded, thus the life-world is a 'horizon of understanding' (Husserl 1970).

The apparent paradoxical nature of the life-world is described by Valle & Halling (1989) who suggest it is both independent of knowledge derived from reflective thought processes and yet is pre-reflective, being the starting point for all knowledge. In relation to medical practice they suggest 'scientific knowledge could not exist without the pre-reflective life-world' (p10).

An adjunct to the life-world of practice is the concept of 'habitus which is defined as the shared and practical [practised] embodiment of the groups' customary behaviour. It is a collective response inculcated by the context of contemporary health care practice' (Bourdieu 2006). Jenkins (2002), suggests that our habitus, the 'common sense' way we interpret and make sense of the world, is affected and effected by the very specific elements which make us individual such as our gender, class, age, ethnicity, political and professional structures. Wacquant (2011), in an ethnographic study of boxers, identified there are necessarily some historical, social and contextual boundaries to our habitus which in turn provides infinite possibilities for influencing inherent creativity by thoughts, perceptions, expressions and actions (Jenkins 2002). The consultant's 'habitus' is co-constructed by the environment and society. There appears to be a shared understanding and confluence between 'habitus' and the life-world that shapes their clinical medical practice.

Merleau-Ponty (1962, 1995) identifies the intimate connection between perception and language in understanding our being and the life-world. What was vaguely known at the pre-language sensing level becomes clearer, verbalisation and explanation of meaning changes the experience. Most view language occurring as a secondary event as there is an element of searching

for the right words in making clear an experience or phenomena. This searching in adults is unconscious and we are only aware of it in circumstances where the right choice of word is important. For the participants in this research, this difficulty may be associated with finding the words to share bad news or disclose an end of life prognosis. This is more fully explored in Chapter 11.

The awareness and understanding of the life-world is a necessary condition for knowledge. The life-world is a perception, precedes knowledge and is 'being to the world' explicating how we relate to and interact with the world and how that relationship shapes our understanding and meaning (Merleau-Ponty 1962, 1995). This links with later parts of this chapter which will explore the philosophical, contextual and tacit dimensions of knowing.

The basic intentional structure of consciousness is explicated by reflection or analysis and involves further shaping. Thus, phenomenology develops a complex account or picture of experience: temporal awareness (within the stream of consciousness), spatial awareness (notably in perception), attention (distinguishing focal and marginal or 'horizontal' awareness), awareness of one's own experience (self-consciousness, in one sense), self-awareness (awareness-of-oneself), the self in different roles (thinking, acting), embodied action (including kinesthetic awareness of one's movement), purpose or intention in action (more or less explicit), awareness of other persons (in empathy, intersubjectivity, collectivity), linguistic activity (involving meaning, communication, understanding others), social interaction (including collective action), and everyday activity in our surrounding life world (in a particular culture) (Stanford Encyclopedia of Philosophy 2008).

Applying this intentional structure of consciousness, the phenomenological dimensions of awareness, to medical practice indicates there is a clear complementarity. Simplistically it may be described as the what, why, how and who of awareness and their influence on our relationship with the life-world.



These structures of consciousness appear closely related to the phenomenological dimensions of the life-world described by Ashworth (2003, 2006, 2008). Building on the earlier insights of Husserl, contemporary phenomenological theorists propose that there are certain necessary characteristics of the life-world which facilitate our understanding of it (Ashworth 2003; Ashworth & Cheung Chung 2006; Ashworth 2008; Todres 2007a; Dahlberg et al 2008). Ashworth (2003) identified eight aspects, or fractions, of the life-world, being heuristically derived and linked to human existence as being:

- Embodiment: how does the situation alter one's relationship to and understanding of one's body?
- Temporality: how is one's sense of time, biography, duration affected?
- Spatiality: how is one's understanding of places and of space affected by the situation?
- Sociality/relationality: how are one's relations with others changed by the situation?
- Selfhood: what does the situation mean for one's sense of self, one's identity and agency?
- Project: how are the things one is committed to and which are central to one's life affected?
- Discourse: what language and discourses are used to describe and live the situation or experience?
- Mood: how does one's mood alter one's way of being in the world?

(Adapted from Virginia Eatough's course material, Masterclass April 2011)

Ashworth (2003) discusses how the fractions of the life-world impact on a situation, in this thesis they will be used to explore the consultants' situations, their experiences, and promote understanding.

Finlay (2010), from an interpretative perspective, proposes at least five different dimensions of Being-with, suggesting there may be value in embracing them more actively in our research encounters. On reflection they also appear to resonate with, and inform, elements of the clinical encounter.

Being-with encompasses:

- *Embodied Being-with* (which involves responding to each other on physical and nonverbal level)
- *Person-to-person Being-with* (connecting with the other at the level of cognition and emotions)
- *Intra-personal, transference Being-with* (unconscious dynamics are played out between)

- *Structural, cultural Being-with* (where aspects related to social positioning are involved)
- *Transpersonal Being-with* (connecting with the other at a more soulful or spiritual level)

Thus used together these phenomenological and interpretative life-world approaches attempt to work out the dimensions of awareness that construct individual experience. A person's thoughts and feelings being made clearer by reflection and analysis contribute to a way of helping them understand their experience. The implication is that this experience is evolutionary and not static and that it is through experience that the surrounding world becomes meaningful (Dahlberg et al 2008).

Theories about life-world and intentionality precede each other. They are confluent each with the other, both impacting on experience but also offering a unique perspective. Intentionality as a phenomenological term refers to the relationship between an individual and the object or events of his/her experience. In this thesis it is their personal experiences, clinical and professional practice that informs and is informed by this connection (Ashworth 2003, Dahlberg et al 2008). Translating to medical practice, their clinical experience is comprised of signs and symptoms of disease and its progression, the context of health care, the individual patient and their world. Their experience is contextualised and influenced by the macro, meso and micro levels of health care as outlined in the introduction to the thesis (Pilgrim & Rogers 1999).

For this thesis, the dimensions of the life-world will act as a 'lens' with which to view and interpret the data. This is consistent with the phenomenological and interpretative activities associated with IPA (Smith et al 2009) and the reflective life-world approach. This supports the aim to be sensitive, open and curious throughout the 'research journey', and this author's engagement with the participants and their experiences (Dahlberg et al 2008; Moodley 2009).

The temporal, spatial and linguistic dimensions of the life-world will perhaps be more dominant in the exploration and subsequent discussion. The

temporal will focus on the consultants' personal and professional biographies, their life experience and lived experiences. The spatial relates to the clinical aspects of professional practice and the multi-professional pluralistic health and social care context in which that practice takes place. The linguistic dimension explores the language and discourse used to describe and live their situation (Ashworth 2003; Dahlberg et al 2008; Moodley 2009). On consideration these dimensions are unlikely to reflect the full account of the essence of life-world of each participant, or of all participants, and it is important to be mindful of Merleau-Ponty's (1962, 1995) assertion that the verbalisation and explanation of meaning changes the experience.

When we are aware of something (an object) we are in relation to it and it means something to us. In this way, the individual (the subject), and his/her world (the object), are mutually co-constituted or co-created. It is a world that is lived and experienced. It is 'not an objective world "out there", but a humanly relational world' (Todres et al 2007:55). In the life-world, the individual's awareness is always focussed on something in or about the world; it is always awareness of something.

The phenomenological concept of intentionality, focuses the data analysis and subsequent discussion in this thesis. Husserl (1998) describes *noesis* and *noema* as two aspects of intentionality. Noesis is the process of thought, while the noemata are the things that are thought about, both are a means to explain objective meaning. Thus, *noesis* and *noema* correspond respectively to experience and essence which form the foundation for understanding.

Hermeneutics is about understanding, it tries to elucidate and make explicit our practical understanding of human actions by providing an interpretation of them. The understanding of the experiences of the consultants was achieved by constantly listening (and re-listening) to their interviews, describing and interpreting their experiences – this is the essence of IPA in that the researcher is making sense of the participant who is making sense of their experience, the double hermeneutic activity.

This approach appears congruent with an understanding of the structures of the life-world, the individual's experience, as discussed earlier in the thesis. The hermeneutic circle is an acknowledged way of thinking about data in IPA research. Valle & Halling (1989), writing earlier, describe it as more of a hermeneutic spiral, that in the search for understanding we never return to the place we started. It would appear that the search for understanding is more akin to the DNA double helix whereby the descriptive and interpretative elements are interlinked or entwined to achieve understanding (create life) but each individual base pair element, the building blocks, are crucial and important to the creation of a particular or unique understanding (life). The base pairs supporting this understanding are the temporal, spatial and discursive elements of the life-world, matched with the elements of clinical thinking, knowing and decision making. The embodied element of the life-world is where being and knowing meet and link specifically with the interpretative element of the participant's experience.

### **3.4 KNOWING**

This element of the literature review will attempt to distinguish between the different types of knowing and knowledge, how it is acquired and mediated and finally how it is applied in clinical practice and becomes part of the consultants' professional activities.

Knowing is distinct from knowledge. Knowing is an individual human process of perceiving and understanding oneself and the world in ways that can be brought to some level of conscious awareness. Not all that is comprehended in the process of knowing can be explicated, shared or verbalised (communicated). When knowing is shared, communicated and expressed linguistically or in actions and outcomes it becomes the knowledge of a discipline (Chinn & Kramer 2008).

#### **3.4.1 Philosophical and historical antecedents of knowing.**

In Western philosophy understanding is supported by the premise of multi-faceted and imaginative knowing. The philosophical and historical exploration of knowing initially proceeded in a systematic manner identifying how

chronologically theories evolved. Later it became more of a recursive approach characterised by the challenging, supporting and evolving of theories, with much philosophical debate appearing partisan or polarised in approach (Welbourne 2001; Shand 2002).

Early philosophers, such as Socrates (470-399 BC), supported the idea of rigorous self-enquiry and questioning of ideas to establish knowing, stating 'that the unexamined life is not worth living'. Two millennia later this has been incorporated into the idea of reflection. The justification of a belief confers on it the status of knowledge and forms the basis for modern epistemology. This idea is also supported by the relativist philosophy of Plato (427-347 BC) who locates knowledge within frameworks of understanding that are influenced by our history, culture and critical perspectives. These chime with the concepts of the life-world and 'habitus' discussed earlier.

Aristotle's *Metaphysics* (384-322 BC) in considering the application of knowledge suggests there are three possible benefits from its acquisition. Firstly, knowing is desirable to gain understanding of the world (which is consistent with the earlier ideas of Socrates and Plato). Secondly, it is useful to solve relevant problems which he describes as *phronesis* or practical reasoning. Thirdly, knowledge is of benefit simply for its own sake without having a practical purpose, this being theoretical or real knowledge (Aristotle *trans.* Lawson-Tancred 2004). Aristotle's notion of *phronesis* became one of the catalysts for Montgomery's (2006) contemporary debate and exploration of '*How doctors think*'.

Descartes' (1596-1650) relativist explication of knowing accepted nothing as true. The difficulties in recognising the truth for him involved undertaking a multi-layered reflective process moving from the simple to the complex. Later authors categorised these processes as intuition, deduction and enumeration and formalised the process of reflection as a means for enhancing knowledge and understanding (Keeling cited by Schon 1987). Polanyi (1974) and Kuhn (1996), appear to return to this relativist tradition as part of considering scientific uncertainty in relation to professional practice.

In contrast, Locke (1632-1704) saw empiricism as the belief in absolutes and truths that are justified by examination of the human mind and the privileging of experience as the essence of reason and knowledge. Kant (1724-1804) criticised the superiority afforded to experience proposing that knowledge is a combination of experience and reason. That knowledge does not always originate in experience, it contains elements of certainty, patterns that can be universal, that exist prior to experience, prior to thought, that relate to intuition, these he describes as 'pre-existing elements in the mind'. It is knowledge that pulls things together and provides a link with aspects of the life-world.

In the early 20th century the logical positivist movement held the highest regard for facts, empirical data and experiments as the basis of science, supporting the empirical hypothetico-deductive approach. Popper (1902-1994), rejected the idea of the empirical consensus that scientific theories could be proved true. His theory of falsification relies on the belief that even when a scientific principle had been successfully and repeatedly tested it is not necessarily true; rather it had not yet been proved to be false. Knowing as described by Popper appears objective, in that it was independent of the subject and had both an ontological and 'truthlike' status. Thus for him the growth of human knowledge proceeds from our problems and from our attempts to solve them. Chomsky (Krauss & Carroll 2006) also believes that a scientific background is important to teach proper reasoning, but agrees that science in general is inadequate to understand complicated problems like human affairs. Scientific information has a place in medicine, in clinical thinking and knowing, in that it reduces but does not remove uncertainty.

Dewey (1910) supported and evolved the earlier pragmatic belief of *phronesis* that knowledge is only significant when coupled with action and that nothing is either true or false – it either works or does not. In essence practical application was all. This resonates with knowing in and for practice and the experience of the consultants.

Kuhn (1996) contributed to the development of understanding the progress of knowledge, moving on from the positivist scientific tradition. His epistemology

of science being dynamic not linear, postulating that periodic revolutions (later described as paradigm shifts) suggest new approaches to understanding and puzzle solving that had not been considered before. He highlighted the idea that knowing is relativistic not absolute and that the idea of being value free is misguided, that the subjective perspective can never be discounted.

Polanyi (1961, 1974) also opposed the traditional positivist explanation of science in that it failed to recognise the importance of personal perspectives. He stated, like Popper, that scientific objectivity is a false belief as it is mediated by personal experience and 'tacit (silent) knowledge', that is knowledge which is understood and implied without being explicitly stated or known. He refines this idea as being 'personal knowledge' which is supported by identifying phenomenological, instrumental, semantic and ontological aspects which are influential in the development of tacit and personal knowing (Polanyi 1974).

Both Kuhn and Polanyi concur that scientists' subjective experiences contribute to the contemporary position of medicine and health care as relativistic and evolving disciplines. Toulmin's (1976) evolutionary holistic perspective and approach to knowing (in contrast to Kuhn's revolution) suggested that the future development of science should be heuristic and needs to acknowledge and support continuity and change. He identifies the dilemma of separating the practice of knowledge from its theoretical base as similar to separating science from epistemology. For him knowing and understanding occurs primarily on an individual level, akin to Polanyi's (1974) personal knowing, prior to it moving into the 'real world', linking with the phenomenological concepts of habitus and life-world (Jenkins 2002; Ashworth 2003). This idea is supported by historicism, a philosophy of science that ascribes importance on the context and processes in which scientific, hence clinical, activity takes place (Toulmin 1993).

Contemporary philosophers of science, exploring doctors' stories, from an analytical perspective, appear to concur that all knowledge, empirical and human, is inevitably subjective and contextual (Fox 1980; Schön 1987;

Cassell 1991; Hunter 1991; Malterud 1995; Montgomery 2006). In relation to health care, knowing is context-mediated, informed by tradition and by knowledge transfer or acquisition from many sources (Hood 2010). In an attempt to categorise the concept of knowing, and locate it in health care practice, Hood identifies three processes derived from philosophy. Rationalism, the belief in the possibility of knowing truth by thinking and reason that is independent of experience, empiricism, believing that the only source of certainty about knowledge is immediate verifiable experience and intuition, 'just knowing' that is subjective and personal, validated through experience and interaction with others. These processes are linked to the different types of knowing that characterise medicine. They are not only related to the series of actions associated with scientific inquiry but are subjective and influenced by the interpreter's prior understanding.

There is also the need for knowing to go beyond technical learning to what is described as 'communicative knowledge' (that is, the knowledge that results from engagement and interrelationship with others) and as 'self-reflectivity' (that is, the knowledge of deep understanding, including of self as knower) (Habermas 1973a; 1973b). This is contrary to the historical idea of *a priori* knowledge that rests on empirical justification that is independent of experience.

In answering the question, 'is knowledge dependent on the knowing subject or independent of it?' the ontological assumption proposes that knowledge can be divided into two types, objective and subjective. Objective knowledge is logically constructed through the belief that certain things exist apart from human knowledge or our perception of them, that it is possible to separate evidence from beliefs and that generating evidence is the core of knowledge. The second type, subjective knowledge, is inductively constructed through reason, with some authors suggesting that knowing *is* subjective knowledge (Berger & Luckman 1966; Polanyi 1974; Popper 2002). This feels rather reductionist in approach and will be further explored in the next section which attempts to explore knowing in relation to clinical practice.



### 3.4.2 Clinical knowing: knowing in and for practice

The underlying questions to be explored in this section of the literature review that are also explored by the thesis are: what kind of knowledge is medical knowledge and is it unique? In considering this epistemological question from a deeper perspective the exploration also considered the experience of being a medical consultant and their life-world, their way of being in the world, explored in the first part of this chapter.

As has been demonstrated in the previous section knowing and thus knowledge is 'a multidimensional dynamic construct' (Sturmberg & Martin 2008:767). Practices are activities engaged in by human beings, there is a difference between practice that relates to physical objects and those that relate to human beings. This early distinction was first recognised by Aristotle who used the word *poiesis* to describe production or manufacturing based activities and *praxis* that describes activities pertaining to human beings. Each of these activities requires different kinds of reasoning and different sets of skills to accomplish them. Making something requires knowledge of the steps and skills for transforming raw materials into an object, described by Aristotle as *techne*. Actions, as in clinical medical practice, which aim to support the human good in a specific situation he describes as *phronesis*. This is the practical knowledge required to support clinical activity which can be described as *knowing that* and *knowing how* these relate to actions that seek to accomplish good in response to human needs. From both social psychology and psychoanalytical perspectives Epstein & Ogdens' (2005) study of GPs' managing obesity connect with Aristotle's thoughts and identifies these two distinct kinds of thinking processes. These are the experiential and the rational – experiential being associated with practical wisdom, *phronesis*, and rational with *techne*. (Aristotle 1985, 2004).

Aristotle (2004) emphasised the importance of practical wisdom (*phronesis*), the ability to judge what to do in concrete situations and because practical wisdom cannot be reduced to formal directives, he emphasised that education should aim to inculcate habits and promote the internalisation of ways of seeing, feeling and acting, rather than simply to impart rules (Shand 2002).

Aristotle's approach, two and half millennia later, is endorsed by Montgomery (2006) who asserts that clinical medicine remains an interpretative activity.

Medicine's success relies on the physicians' capacity for clinical judgement. It is neither a science nor a technical skill (although it puts both to use) but the ability to work out how general rules - scientific principles, clinical guidelines – apply to one particular patient. This is- to use Aristotle's word – *phronesis*, or practical reasoning (Montgomery 2006:5).

Montgomery's (2006) work was written and informed by the personal context of her 28 year old daughter's diagnosis of breast cancer which, in the narrative, she acknowledges as having influenced and informed her perspective. This supports the concepts of personal knowing, in the participants' stories in this thesis of the personal impacting on the professional.

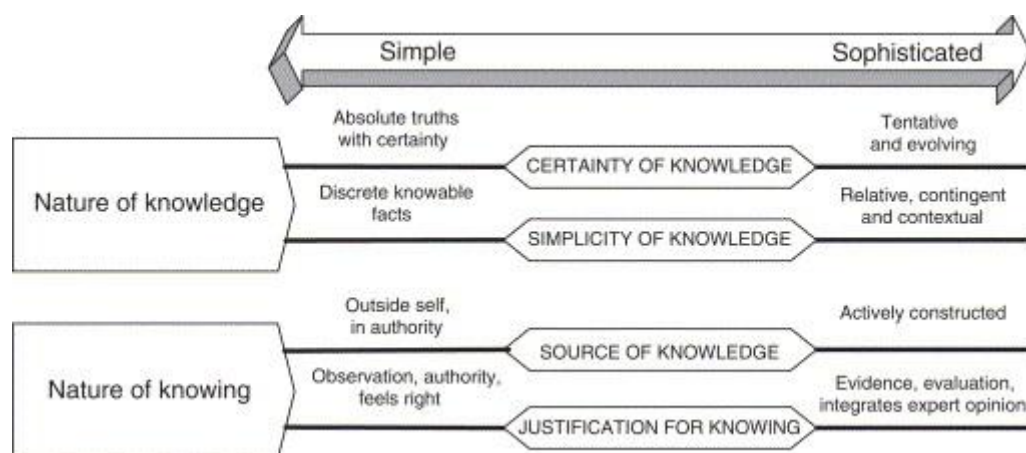
Gabbay & leMay (2011) argue that Aristotle's distinction is useful in making us think about knowledge differently. His idea of *phronesis* focussed on the practical elements of ethical and political decision-making in practice but does not support 'the professional craft or tacit knowledge' (p220) that this thesis is trying to explore and understand.

Michael Polanyi (1974) has argued that we know more than we can tell and that this tacit knowledge underlies all of our more explicit knowledge. Related themes emerge in Gilbert Ryle's (cited by Shand 2002) distinction between knowing-how and knowing-that, which emphasises the characteristic between knowing *how* to do something (for example taking a blood pressure) and knowing *that* some particular proposition is true (such as water boils at 100°C). This is similar to Aristotle's distinction but does not relate to knowing as doing good and responding to human need.

Tacit knowing is also present in Pierre Bourdieu's linguistic and contextual notion of *habitus*, a routine way of behaving often unquestioned because of its inherent nature. Thomas Kuhn (1996) likens the learning of science and

medicine to an apprenticeship in which one acquires not just explicit knowledge but also habits and skills. Both resonate with the model of medical education at undergraduate level and during post-qualification professional development (Dreyfus & Dreyfus 1986).

Clinical knowledge is personal and it is discovered, it has both overt and tacit dimensions. Practical knowledge is divided into *knowing what* – naming facts and relationships and *knowing how* – which is about explaining and performing procedures. In medicine a distinction is made between propositional knowledge, which underpins and enables professional action and practical know-how which is inherent in and cannot be separated from the action itself.



**Fig 3. The four core structural dimensions of personal epistemology: certainty of knowledge, simplicity of knowledge, source of knowledge and justification for knowing (Hofer & Pintrich, 1997).**

In clinical practice all action arises from knowing ways of being and doing that represent what is known and what is knowledge. As discussed in the first part of the chapter it varies across time, place and person. It is also constructed by the individual and for the individual through social processes, systems of language and discourse which is mediated by continual challenge, evolution and reframing.

Clinical thinking and knowledge in practice have been investigated, validated, challenged and disseminated by the use of the ethnographic and phenomenological qualitative research approaches either alone or as part of

mixed methodology rather than quantitative biomedical enquiry (Dreyfus & Dreyfus 1980; Benner 1984; Atkinson 1995; Malterud 1995; Hunter 1996; Malterud 2001; Montgomery 2006; Gabbay & leMay 2011). The researchers involved were from nursing, sociological, psychological, linguistic and medical backgrounds.

Clinical knowledge consists of interpretive action and interaction, factors that involve communication, opinions and experiences. Although evidence-based medicine is widely accepted as the basis for practice, it cannot refute the fact that clinical decisions and methods of patient care are based on more than empirical data (Sackett et al 2000; Malterud 2001; Gabbay & leMay 2011). Although science supplies medicine's 'gold standard', knowledge exercised in the care of patients is, like moral knowing, a matter of narrative, practical reason (Hunter 1991; Montgomery 2006). Tacit knowing is held and applied by proficient/expert practitioners and represents a valuable form of clinical knowledge derived and acquired through experience (Dreyfus & Dreyfus 1980; Benner 1984; Atkinson 1995; Montgomery 2006).

The knowledge impasse for physicians is described by Montgomery (2006), in that they 'must learn not only what course of action will be most likely to benefit the patient (even when the choices are not good ones) but also what to do when information is conflicting or unavailable' (p4). This supports the eclectic approach to knowing taken in this thesis, in attempting to explore and understand what types of knowing influence referral to SPCS. It focusses on consultant (acknowledged by their position as expert) physicians in an attempt to reflect on their experiences and to understand and articulate knowledge about what is going on for them in relation to their practice (Smith et al 2009).

Without considering all of the patterns of knowing, their role in practice would be uncritical with a narrow focus and interpretation with no single right approach, but many choices. In this thesis the overview of the conceptual frameworks of knowing and knowledge suggest a tacit and tentative recognition and significance of these multiple patterns and perspectives.

There is no ownership of knowledge, with many arguments about borrowed versus unique bodies of knowledge (Bonis 2009). This thesis seeks to support the more inclusive and pluralistic approach to understanding clinical thinking and knowledge in practice. This is contrary to the assumption that it is necessary for a discipline to have a unique corpus of knowledge in order to establish a clear and distinct identity (Edwards 2001). It does not however negate the clear distinction and difference between medical practice and that of nursing and other health care professionals.

For medicine the knowing patterns or typologies appear implicit and linked to the narrow philosophical concepts of empirical and tacit knowing (Hunter 1996). Carper's (1978) work initially described and extrapolated four patterns of knowing: empirical, aesthetic, ethical and personal as informing nursing practice. Each pattern has both a theoretical and clinical 'expression'. This broadening of knowledge makes it distinct from pure empirics, the other knowledge patterns being an adjunct or synergistic to empirics - their combined effect being greater than the sum of the individual effects.

Empirical knowing draws on the traditional ideas of scientific knowledge, considering underlying principles and techniques often procedural. Aesthetic knowing expects a deep appreciation of the meaning of a situation and its transformation into practice often creatively, the art of professional practice. Personal knowing is largely autobiographical, acknowledging the validity of feelings, experiences and reciprocity, the knowing of one's own self may enable the knowing of others. Ethical knowing evolved from the moral characteristics of the individual to the professional requirements of duty and responsibility, it is about what ought to be done in practice (Carper 1978). These ways of knowing have been linked to medical practice in ethnographic and observational studies (Hunter 1991; Montgomery 2006) and in exploring doctors' professional judgement (Fish & Coles 1998).

Later authors have evolved these ways of knowing into more contemporary models relevant to 21<sup>st</sup> century health care. Munhall (1993) added 'unknowing' and White (1995) identified socio-political knowing. Belenky et al

(1997) formulated a theory consisting of five types of knowing from which women perceive themselves and approach the world which linked closely to the work of these theorists who were all women. Most recently, Chinn & Kramer (2008) reframed socio-political knowing as emancipatory knowing derived from recognition of inequities and injustices in health care and the acknowledgement of individual differences and experiences in relation to health care actions. It highlights individual, local, national and global responsibility that links with the macro, meso and micro levels of health care practice (Pilgrim & Rogers 1999). Practitioners are required to function at all these levels which in turn demands complex and sometimes dissonant knowledge.

These 'ways of knowing' will be used to support the discussion section of the thesis. Knowledge is a construction that varies across time, place and person. Medicines ways of knowing rely on two essential tenets. Firstly, practice is complex and thus it follows that its knowledge base is eclectic, relying on more than a single source of knowing. Secondly, empirical knowledge alone is not a sufficiently robust foundation and is inadequate to represent the complexity of the practice arena (Chinn & Kramer 2008).

### **3.4.3 Medical knowing**

The public perception of medical practice is that it is grounded in a rigorous scientific knowledge base (Hunter 1991; Gabe et al 1994; Atkinson 1995; Lupton 1997, 2003a; Montgomery 2006) that negates other aspects of knowing. Dreyfus & Dreyfus' (1980) model, if used as a philosophical approach rather than a theory, enables an exploration of ways and patterns of knowing beyond the empirical and considers its application and interpretation in practice.

Wyatt (1991) describes two types of medical knowledge. Low level knowledge is about the structure and function of the body, diseases and their causes, special investigations and treatments and is all acquired during under and postgraduate training resonant with the hypothetico-deductive approaches, as well as knowing derived from the logical positivistic paradigm.

High-level knowledge is derived mostly from clinical experience which enables skilled practitioners to organise evidence and make wise decisions using the processes of 'knowledge soup' leading to pattern matching. Her approach links with the idea of expertise moving the debate beyond the novice to expert levels of practice described earlier (Dreyfus & Dreyfus 1980; Benner 1984; Dreyfus & Dreyfus 1986).

Medicine, not uniquely or privileging, is more of an art with skills passed on through apprenticeship that acknowledges the importance of senses and feelings in developing expertise (Atkinson 1981; Gordon 1988). From a sociological perspective Atkinson suggests that contemporary clinical practice is underpinned by personal, traditional and scientific knowledge. Bloor's phenomenological perspective recognises that professionals have stocks of 'recipe knowledge'. Atkinson reconceptualises this as being recipes for action, a cookbook for knowledge and action (Atkinson 1984).

Consistent with public perceptions of medical practice, there is a misleading distinction made between hard, external, scientific (objective) evidence and softer, value-laden, personal (subjective) evidence. Critical reflection encourages examination of *all* evidence achieving an equipoise that contributes to knowing in practice and guides, or ought to guide, best practice (Avis and Freshwater 2006). The aim of the methodological approach, IPA, used in this thesis seeks to bring out the value and achieve understanding of the consultants' subjective (softer) personal experience and how it links with clinical thinking and knowledge in practice.

This more personal approach is demonstrated by Hunter's (1991) ethnographic narrative study of the interaction between physicians' teaching and learning to take care of patients. She questioned how medical knowledge is acquired and observes how doctors are 'professionalised'. Her approach demonstrated that medicine is not based on scientific principles or knowing alone, it relies on interpretive elements which facilitate the doctor's understanding of their patients. She describes medicine as:

interpretive activity, a learned inquiry that begins with the understanding of the patient and ends in therapeutic action on the patients' behalf (Hunter 1991:xx).

Hunter asserts that medicine is not and should not be a science. It is not just about diagnosing an illness, it is about that illness being understood and treated, that is the interpretive (non-scientific) element. Her observations identified that doctors begin with the effects of illness, the symptoms, and investigate backwards to elicit the cause. The distinction she makes between interpretive and scientific, objective knowing is based on the misunderstanding of it being a science which has reductionist consequences whereby the clinical focus is on the diagnosis of disease rather than the care of someone who is ill. Her call for a more holistic and human approach to medical practice initially met with little success but is now much more an accepted concept in medical practice and supported by phenomenological inquiry (Fish 1998; Polkinghorne 2004; Gabbay & leMay 2011).

Hunter (1991), in her introduction to *Doctors' Stories*, observed the practitioners role as 'observing, testing, interpreting, explaining and taking action' on behalf of their patients. Her thesis describes medicine's ways of knowing and its methods of transmitting that knowledge. Clinical medicine is the exercise of practical knowledge and medical education leading to the inculcation of a craft linking back to the apprentice model (Dreyfus & Dreyfus 1980; Benner 1984; Cassell 1991; Kuhn 1996). Montgomery's work supports the idea in this thesis of the pluralistic nature of clinical knowing and thinking that supports the focus on the individual patient.

Lupton's (1997) sociological empirical study attempted to elicit Australian doctors' experiences of medical practice in the late twentieth century. It was contextualised by apparent increasing cynicism towards the expert knowledge of medicine in Australia. In describing what made a good doctor, the central tenets were empathy and good communication especially in relation to the ability to make difficult medical decisions in the face of uncertainty. Therefore, intrinsic to contemporary medical practice is the requirement for professional



reflexivity on their clinical experience which enables them to develop knowledge of and deal with patients' individual needs and expectations.

In an attempt to arrive at a conceptualisation of knowing that fully embraces the whole of health care practice Upshur (2000) appears to have been influenced by Carper's *Ways of Knowing* (1978) in developing a conceptual model of evidence in practice. The approach was different in that it considered the concept of evidence, rather than knowing, identifying that both are derived from a broad epistemological base. The idea of empirical evidence was extended to include philosophy, interpretation and political theory, this was a conceptual shift from the traditional biomedical model. The justification for this stance derives in part from the move to more inter-professional working within a holistic framework that underpins contemporary pluralistic health care practice. These chime with modified ways of knowing outlined by Chinn & Kramer (2008).

This is contrary to the apparent contemporary dominance of evidence-based practice (EBP). EBP emphasises the value of scientific evidence which, although appropriate in ensuring the individual receives correct treatment and thus effective care, perhaps undervalues the role of clinical judgement and individual expertise. It de-emphasises the non-scientifically determined sources of knowing in relation to clinical decision-making and interpretation of empirical evidence (Sackett et al 2001; Kirkham et al 2007).

Di Censo et al (2005) developed a model of evidence based clinical practice and decision making that requires knowing in all knowing domains, whilst acknowledging the centrality of clinical expertise. This is clearly an attempt to reconcile the two binary opposite paradigms of evidence based practice and holism which has been further developed by Gabbay and leMay (2011). By ethnographically examining how clinicians develop and use clinical knowledge in their daily practice, Gabbay and leMay (2011) concluded that they use 'mindlines'. These are internalised, collectively reinforced tacit 'virtual' guidelines. They exemplify the composite and flexible knowledge that

clinicians require in and to practice, offering an appreciation of both the individual and shared 'community' of practice:

Mindlines also have a much deeper and more pervasive function than merely guiding the diagnosis and management of patients: they both embed and express professional norms and values (Gabbay and leMay 2011:169).

The collective norms (outlined in the table below) enable professionals to practise in a way that meets the demands they face as individual practitioners and team players. This thesis seeks to explore the experiences and decision-making practice of the consultants in order to make known and embody their life-world and 'habitus' to achieve a reciprocal understanding.

**Table 3: Ways of conceptualising mindlines using Spradley's (1997) analytical framework cited by Gabbay and leMay (2011:45)**

Mindlines are 'kinds of':

- experiential knowledge in practice
- prior knowledge 'in my head'
- 'grit in the brain'
- personalised mental checklists
- elastic practical routines
- amalgams of different kinds of knowledge
- flexible pathways that encompass all the practical roles
- adaptable, fuzzy logic that accommodates conflicting roles
- socially constructed patient pathways
- triggers for different strategies for care.

They are also:

- bounded areas of acceptable practice
- rooted in early training
- developed through grazing many types of professional, scientific and commercial literature, including published guidelines
- discussed and shared at relevant meetings
- modified by exchange with colleagues and experience with patients
- collectively as well as individually held
- adapted - but also reinforced or entrenched – by continuing education
- checked against trusted sources of expertise
- flexibly adapted to individual patients
- open to plasticity of performance
- capable of absorbing change but tending to revert to the 'default setting'
- affected by social, economic and organisational demands
- shaped by local factors
- ways to change practice

This mindline list has helped identify an appropriate way of looking at the research participants' stories of their experiences. It has also provided a clear representation of the complexities, challenges and difficulties intrinsic to professional practice and decision making. It has enabled the thesis to be presented in a way that is inclusive of the concepts of knowing, expertise, decision making, life-world, 'habitus, language and metaphor. Mindlines provided a virtual gestalt to support understanding of the experience of the

research participants. With the increasing dominance of the virtual world in twenty-first century society, a virtual construct such as mindlines for explicating clinical thinking and knowledge seems apposite. In this thesis, as a framework, they enabled construction of conceptual mind maps that helped deepen the exploration and understanding of the participants' experiences.

### **3.5 DECISION MAKING**

Medical consultants, having the clinical responsibility for their patients' care, use clinical knowing and thinking to make decisions about that care - specifically in this thesis decisions regarding referral to specialist care. The next section will explore decision making in the context of medical uncertainty and judgement based care. Expertise and competence is included because as medical consultants these elements are acknowledged as a requirement of their role and might influence their decision making (Eraut & duBoulay 1999).

Psychological literature has focussed on decision making as an exemplar of medical expertise, suggesting there is a development of knowledge, diagnostic skill and intuition along a linear continuum from novice to expert (Dreyfus & Dreyfus 1980). Lakoff & Johnson (1999) argue that human thinking is a bodily, as well as cerebral, activity and is defined by a universal set of characteristics irrespective of the particular knowledge base:

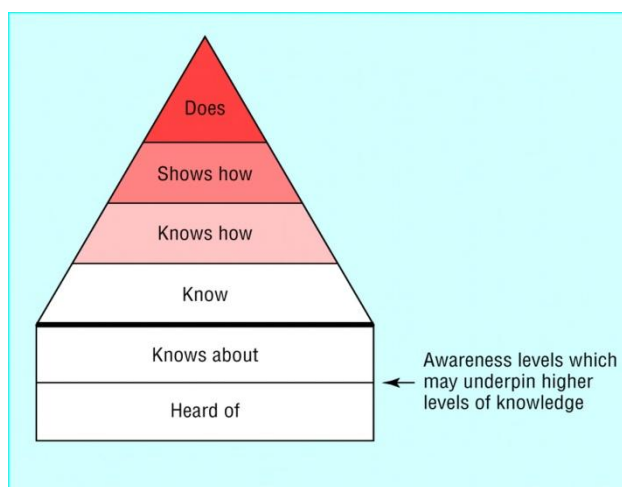
- Thinking arises from the nature of individuals' brains, bodies and bodily experience
- It is an evolutionary process and that is shared by other developed forms of life
- Thinking is not universal but is a capacity shared by all human beings - it operates mostly out of awareness
- Thinking is emotionally informed in meaning making
- It often uses metaphor and imagination as a way of illustrating thinking.

These characteristics appear directly relevant and impact on how professionals think and act in practice.

Dreyfus and Dreyfus' (1980) model of developing expertise provides a means of assessing and supporting individual progress in the development of skills or competencies and offers a definition of an acceptable level for the

assessment of competence or capability. The 'expert' level does not signify that development stops at expert practitioner level as they too need to evaluate their practice and keep up-to-date with new experience.

Expertise linked to competence is further developed by Miller (cited in Peile 1990), his hierarchy of competence (see below), is represented as a pyramid. The levels are cumulative indicating that the lower levels need to be achieved as the foundations on which to be built. The expert practitioner would work and demonstrate competence at all levels.



**Fig 4: Miller's pyramid of assessable competencies adapted to include levels of awareness. Peile E BMJ 2006;332:645 (18 March), doi:10.1136/bmj.332.7542.645**

An expert is someone who is recognised not just by what they do, through their actions, it is about the knowing and the knowledge that underpins those actions. A process of knowing develops the knowledge. Triggers promoting physician learning distinguish between those prompted by problems raised by current individual patients and those required to improve proficiency in a specific area of practice. Expertise in medicine is domain specific. For the cardiologists, oncologists and old age psychiatrists their specialist practice is legitimised by the substantive field of knowledge they possess and command and the techniques they possess in applying that knowledge into the specialist area of practice. Experience is thus not the sole determinant of expertise, it is how that experience is manifested in practice that demonstrates expertise.

Competence is defined as the 'ability to perform the roles and tasks required by one's job to the expected standard' (Eraut & duBoulay 1999:11). In medicine this is usually achieved through independent action. There is a clear distinction in medical practice between competence, (what a doctor can do), and performance, (what a doctor does do). Clinical performance is impacted on by many factors both internal and external. This links with Chapter 2 which explored the structural context of care.

Experienced knowing is clinical judgement. Medical expertise includes both competence and clinical judgement. Its knowledge base is characterised by much uncertainty, its application is influenced by professional judgement and the use of practical reasoning in the care of patients: 'the wise decision made in the light of limited evidence by an experienced professional' (Eraut 1994:17).

### **3.5.1 Medical uncertainty**

Aspects of medical practice are characterised by apparent uncertainty (Timmermans & Angell 2001). This is particularly evident in care at the end of life especially related to prognostication (Christakis 1999). This uncertainty has been characterised by Hall (2002) into three elements:

1. technical uncertainty occurring from inadequate, incomplete and fast moving scientific knowledge which for this thesis may relate to the difficulties associated with prognostication
2. personal uncertainty which is intrinsic in the doctor/patient and inter-professional relationships
3. conceptual uncertainty which arises from a difficulty in applying abstract criteria to concrete situations. This is illustrated in this thesis by the application of clinical guidelines and pathways for care and the application of past experiences to current patients.

An additional facet of conceptual uncertainty that impacts on end of life care is the universal, 'existential' uncertainty of the future which impacts on all clinical decision making. It is conceptual uncertainty that appears to remain constant despite increasing experience, whereas technical and personal uncertainty may lessen (Beresford 1991; Hall 2002; Ghosh 2004). In particular end of life care is affected by the establishing of a prognosis or 'diagnosing dying' as much clinical diagnosis is inference. Ghosh (2004) suggested an additional

element of behavioural uncertainty on the part of clinicians that may have a greater direct impact on patient care.

These categories highlight the complexity of uncertainty and its impact on practice. Writing initially in the 1950's, and more recently, Fox (1980) highlights the apparent dichotomy with uncertainty being both a *problem* in clinical practice but also an almost *essential quality* of medical knowledge and practice. She suggests medical training for uncertainty being a necessary part of the curriculum (Fox 1980). In much sociological writing there appears an implicit negative connotation associated with medical uncertainty. However, by reframing the concept it is possible that uncertainty is right and proper in medical practice that deals pragmatically with human beings in difficult circumstances within the context of incomplete and limited medical knowledge.

The distinction or binary opposites (discussed later in Chapter 11) between theory and practice or between empirics and experience is not drawn in order to contrast 'certainty' and 'uncertainty'. Both are ways of supporting knowledge in and for clinical practice. Atkinson (1984) argues that student doctors and practitioners are not paralysed by this uncertainty:

Personal knowledge and experience are not normally treated as reflections of uncertainty, but as warrants for *certainty*. The primacy of direct experience is taken to guarantee knowledge which the student and practitioner can rely on (p953) (authors' emphasis).

There is some evidence that as practitioners acquire greater knowledge and experience this uncertainty diminishes. Their remaining uncertainty is linked to the limitations of medical knowledge itself and the complexity of the human experience which is not amenable to management. This links with the idea of medicine being more than an art and a science - it is so much more (Montgomery 2006; Wellberry 2010).

Literature and professional practice suggests there are clear links between uncertainty, expertise and clinical intuition. It appears that some problems in professional practice are often as a result of the fallibility of routinised

behaviour and reliance on purely intuitive decision making. Intuitive thinking is often described as feelings, hunches or tacit knowing. Intuition itself is described as engaging in the complex use and interpretation of evidence and in the integration of diverse sources of qualitative and quantitative data (Atkinson & Claxton 2000).

From a sociological perspective medical knowledge appears to have been influenced by Foucault's critique of scientific knowledge and the exercise of professional power. Social constructionists acknowledge that experiences such as illness, disease and death exist as biological realities, but also emphasise that usually such experiences are given meaning and therefore understood and experienced through cultural and social activities (Lupton 2003). Bury (1986) suggests the social constructionist perspective of understanding, experience is compromised by its lack of acknowledgement of the 'real world' and its complexities.

Expert knowledge in relation to medical practice is often carried out intuitively and practitioners' knowledge of how to do it is tacit. The consultants would be hard pressed to explain their knowledge base for practising in a particular way or how they acquired the expertise to do so. Eraut (1994) describes expertise in practice as being confident in creating context-specific knowledge and developing instantaneous professional judgements. This idea has been further developed by Fish & Coles (1998) as being the 'right thing to do' which is intrinsic to the professional's relationship with patients or clients:

Professionals are educated, held in high esteem, and well paid, largely so that they are able to make appropriate judgements in situations where there is no right answer, where difficult choices must be made, where there is a moral dimension to the practitioner's actions (p4-5).

It is apparent that fundamental learning experiences are, and will remain, the doctor's direct contact with and experience of a wide range of patient cases in the context of clinical practice: learning in and for practice (Atkinson 1984; Benner 1984; Hunter 1991). This supports Eraut and duBoulay's report for the DH (1999) who inextricably link expertise and experience. Thus,



understanding the nature of expertise is important for self-monitoring one's use of heuristics and possible bias, sharing knowledge with others and supporting other peoples' learning (Fish 1998; Fish & Coles 1998; Atkinson & Claxton 2000; Montgomery 2006; Gabbay & leMay 2011).

### **3.5.2 Judgement-based care**

Contemporary clinical debate appears polarised by trying to determine whether the approaches to practices of care should be technically based or judgement-based. Technically based practice is rooted in scientifically validated techniques and programmes that have been evidentially demonstrated to accomplish a specified goal. It has recently gained dominance and is represented by evidence based practice, guidelines, protocols and in research systematic reviews. The institutions and organisations that oversee medical practice, govern their activities with the requirement to achieve outcome-based and quality indicators as a way to demonstrate best practice. Polkinghorne (2004) suggests this focus appears to view clinicians as 'the strategic means for achieving institutional goals' (p129).

Health care systems adopting this approach argue rightly that it is in no-one's interest, especially not the patient's, to receive ineffective care. It is an imperative that care has a robust evidence base and provides the individual patient with the correct treatment. For example, specific techniques, procedures and programmes are evident and recommended by NICE in relation to all of the clinical specialities explored in this thesis. In cardiology, especially heart failure, the use of specific medical and device therapy appear to have prolonged life - for example cardioversion. In oncology the use of combined rather than single agents in administering cytotoxic chemotherapy has led to improved therapeutic responses and lessened side-effects. In old age psychiatry, the use of new drugs such as Aricept and Ebixa has delayed the progression of dementia in a small number of carefully selected individuals. In palliative care the use of subcutaneous syringe drivers in managing patients' symptoms in the last days of life and the integrated care

pathway for the last days of life have made for improved patient and care experience (Chan & Webster 2010).

The Aristotelian notion of praxis is defined as being informed, committed action. It is not simply action based on reflection, it embodies certain qualities. These include a commitment to human well being and the search for truth, and respect for others. It is the action of people who are free, who are able to act for themselves. Praxis has been influenced by the post-modernists and updated in the last fifty years to incorporate theory and action; why you *do* what you do as well as *what* you do. It is always risky. It requires that a person 'makes a wise and prudent practical judgement about how to act in *this* situation' (Carr & Kemmis 1986:190). Praxis therefore links to clinical decision making, how clinical judgements are made.

Antecedents to judgement-based care include the technical rational (TR) and professional artistry (PA) models of professional practice (Fish & Coles 1998). The TR model places importance on visible elements of practice, essentially the mechanistic (technical and skills) elements, being evidence-based, supported by guidelines and protocols and demonstrable outcomes. The practitioner's performance is judged by Individual Performance Review (IPR) against agreed Professional Development Plans (PDP) and competency frameworks linked to the requirements for periodic re-registration.

PA differs in viewing professional practice as being more holistic, being dependent on the invisible elements of practice and supported by a reflective, investigative approach that encourages practitioners to develop and understand their practice from within themselves. PA does not negate the importance of skills but locates them within a broader professional perspective informing practice (Gabbay & leMay 2011).

Judgement-based practice promotes the belief that practice uses professional judgement in order to accomplish a specified goal - that practitioners' self-knowledge, experience and training will enable them to make flexible judgements about what actions will achieve a specific goal with a specific

person at a specific time in a specific place. Judgement-based practice focuses on the practitioner as being the unique factor that enables the achievement of the goal of care, for example in the establishing and communicating an end of life prognosis and facilitating the transition from curative to palliative care. Judgement based care is postulated as being more flexible and responsive to individual difference and practice uncertainty, thus links with the complexities intrinsic in care at the end of life.

Neither approach, technical rational or professional artistry, appears sufficient in or of itself. Elements from both have value but are still not enough to describe the nature of current practice in end of life care. The suggestion being made by Fish & Coles (1998) and Polkinghorne (2004) that clinical intuition, practical wisdom, expert and experienced practice all impact on judgement based care which in turn is mediated by the professional, their life-world, clinical context and the evidence-based culture of health care. Other literature suggests that it is the knowledge, skills and the relationships patients and families have with practitioners that are uniquely valued and prized (Hunter 1991; Lupton 1997; Montgomery 2006). This human approach is congruent with the philosophy of end of life care.

### **3.6 CONCLUSION**

The human realm of practice is complex and wide-ranging in nature, characterised by the capacity for conceptual thought at both basic and higher order levels. Practitioner knowledge in the human realm requires not only knowing what to do but also what the action means to others. It is about meanings and intentions and is mediated by cultural and individual experiences.

Clinical practice includes all the things that people do, but also why and how they do them (Polkinghorne 2004). Practices are grounded in understandings people have about the world, and these are, in turn, influenced by the effect of their practices on the world. Therefore contemporary practice theory focuses on the point of interaction of people with the world and others. Practice is also

context dependant on what goal is being sought and what is being done to accomplish that goal.

In this thesis, using the IPA approach, the consultants are being asked to describe their professional and personal experiences in practice, demonstrating 'know how' and understanding. This approach is underpinned by the philosophy and perspective of life-world led healthcare which seeks to support a more humanising and holistic clinical practice. The interpretative approach supports the concepts of ways of knowing and ways of being, whereas phenomenology talks about the lived experience.

The next chapter explores the research approach and outlines the specific objectives for the study. These link with the literature reviewed, outlining the structural and theoretical contexts of specialist palliative care and consultants' practice. It is important to acknowledge that the literature review at the start of the thesis was embryonic. It was amended and rewritten, after the processes of data collection and analysis, to reflect the content of the consultants' experiences and understandings. The revisiting of the literature review is consistent with the IPA approach recommended by Smith et al (2009).

## **CHAPTER 4 - THE RESEARCH PROCESS**

**Qualitative study is an activity whose intended goal is the production and communication of an insightful and disclosing understanding of a human phenomenon. Qualitative researchers engage in those activities that they believe will bring about the accomplishment of this goal as it relates to the particular phenomenon they are studying. (Polkinghorne 2006:73).**

### **4.1 INTRODUCTION**

This chapter explores the research process and provides validation for the selected approach of IPA (Smith et al 2009). It offers an outline of the specific objectives for the study and for the development of the thesis. The research design and methods are described and justified. The chapter also includes an explanation of the research governance and ethical review routes and frameworks within which this study was undertaken.

### **4.2 JUSTIFICATION AND SPECIFIC OBJECTIVES**

#### **4.2.1 Overview**

The central question in this thesis seeks to explore 'how participants make sense of their experiences' (Chapman & Smith 2002:126). It engages with the meaning that their experiences, events and actions hold for medical consultants. It also achieves an understanding of what they think or believe about palliative care, referral practices and decision making. If the research question was focussed only on an examination of the experiences themselves, then a phenomenological approach would be the appropriate facilitative method of inquiry. This thesis however sought to deepen the consultants understanding of their experiences and thus required a more interpretative and contextual approach. These requirements linked with and supported the choice of Interpretative Phenomenological Analysis (IPA) as the chosen approach.

The aim of IPA is to achieve congruence between the perspectives of phenomenology and hermeneutics. It supports in-depth exploration of the consultants' lived experiences together with a close examination of how they

made sense of these experiences. IPA is also associated with the social constructivist perspective, being fundamentally concerned with issues of interpretation and meaning, within the context for this thesis, of contemporary pluralistic health care.

#### **4.2.2 Methodological background**

Much of the early research in exploring aspects of death and dying was undertaken using quantitative approaches, providing insights into discrete elements of the patient or family experience (Parkes 1964, Hinton 1967). Owens & Payne, cited in Murray & Chamberlain (1999), (despite the primacy of quantitative approaches in the research literature), recognised that historically studies related to death have consistently privileged the qualitative approach in achieving understanding of the patient and family experience (Glaser & Strauss 1965 [reprint 2005]; Kubler-Ross 1969). Qualitative approaches are still the preferred paradigm for much research conducted at the end of life (although there is some evidence that this is changing).

In exploring the appropriateness of using qualitative methodologies in end of life care research, Owens and Payne (cited in Murray & Chamberlain 1999) identified the strengths of qualitative approaches as placing emphasis on the meaning and coherence of experience in which veracity is not a prime concern. The truthfulness of the experiences described by the participants is rarely questioned in qualitative research as their stories are a reflection of what they perceive and understand their experience to be and thus cannot be proved to be incorrect. The interpretive paradigm argues that there is no such thing as truth in any version told by anybody. This contrasts with the pursuit of a supposed objective truth found in quantitative studies.

Qualitative research, they suggest, minimises the power imbalance between the researcher and researched and acknowledges the importance of the use of language. It supports an explicit approach to reflexivity in which the researcher considers their own mortality and experiences, acknowledging that they may influence the findings and conclusions of the thesis (Owens & Payne cited in Murray & Chamberlain 1999).

Of the qualitative studies published, only a small number, as in this study, are related to the experiences of professionals with prolonged exposure to dying patients (Lyckholm 2001; Jackson et al 2008; Kearney et al 2009). A further small subset, as in this study, is related to decision making among patients and professionals (Michie et al 1999; Epstein & Ogden 2005; Vandrevalla et al 2005; Whittington & Burns 2005). Even less common are those related to how professionals' personal experiences of death and dying impact on their professional role.

IPA has proved useful for exploring issues and experiences at the end of life, although only a limited number of relevant studies have been published (Golsworthy & Coyle 1999; Jarrett et al 1999; Chapman et al 2005). Many of the issues in existing IPA research relate to topics that are multifaceted, dynamic and troubling. IPA studies have explored many complex issues: emotions such as anger, behaviours such as addiction and sensitive health and social care experiences such as sexuality and genetic testing (Smith et al 2002; Flowers et al 2003; Eatough & Smith 2006a; Shinebourne & Smith 2010). As discussed in the introduction, this thesis aims to explore the factors (personal and professional, extrinsic and intrinsic), influencing consultant cardiologists, oncologists and old age psychiatrists' referral practices and decision making in end of life care.

The corpus of existing IPA research (mostly related to health psychology), supports and encourages a person-centred approach to the interviews together with both flexibility and detail in analysis. This suggests the approach is likely to enable the 'best possible' exploration of the consultants' experiences as required by this thesis. As a nurse proposing to work with physicians in exploring sensitive and troubling issues it also offers a more personal approach to both data collection and analysis. The issues the interviews might raise are comparatively new and may elicit sensitive and emotional responses from the participants (Chapman & Smith 2002).

A more detailed rationale for the use of IPA is provided later in the chapter.

#### **4.2.3 The aim and objectives of the study**

The aim of doctoral study is to create and interpret new knowledge. Factors related to referral to SPCS identified in much previous research, focus on clinician barriers especially in establishing a prognosis in non-cancer conditions in which the dying trajectories are unpredictable. It is not clear whether the acute hospital setting adds to the difficulty. The impact of the organisational structure of health care, together with consideration of how consultants' personal experience of death and dying impact on their perceptions of palliative care and referral practices, seem under-represented in research literature. Thus it would seem an appropriate and timely aim to explore the external and internal factors influencing referral as part of this doctoral study. It will attempt to achieve a more complete understanding of their professional and personal experiences.

The cross professional exploration, as undertaken in this thesis, is enabled by a shared knowledge of the topic areas and an understanding of the terminology and complexities of care at the end of life. However, coming from another professional tradition enables a different viewpoint to be brought to the exploration. This supports the idea that although medicine and nursing are similar, there is much evidence (Benner 1994; Fish & Coles 1998; Montgomery 2006) which suggests that their ways of thinking and knowing are 'astonishingly different' (personal communication with Lankshear 2011).

The perceived power imbalance between nurses and doctors suggests the idea of a nurse being given access to the world of medical consultants might appear unusual. On the contrary, in this thesis, as in other contemporary literature there is evidence of physicians welcoming and supporting other professional groups, helping them to explore the nature of medical practice. It is hoped that through publications and conference presentations derived from this thesis nurses will also gain an increased understanding of the world views of their medical colleagues.

Much work exploring the experiences and world of medical consultants has been undertaken by a variety of academic and professional groups. These



include sociologists (Glaser & Strauss 1965; Atkinson 1981, 1995; Lupton 2003), an anthropologist (Hunter 1991; Montgomery 2006), psychologists (Kubler-Ross 1969; deHennezel 1997), educationalists (Eraut 1994; Fish & Coles 1998), philosophers (Toulmin 1976; 1993; Aristotle 2004), physicians and nurses (Gabbay & leMay 2011) and physicians themselves (Kleinmann 1988; Cassell 1991; Christakis 1999). There is less evidence in the literature of nurses directly researching the work of physicians, although there are anecdotal opinions and reviews. Research by nurses has recently been applied to the work of doctors, for example Benner (1984) informing Upshur's work on medical evidence (Upshur 2000). This supports the move towards a more inter-professional and collaborative approach to healthcare practice.

This study's comprehensive activities and objectives are summarised below. These were to:

- undertake twelve, which became ten, minimally-structured interviews with consultants working in secondary care with patients from three patient population groups:
  - Advanced Cancer (4)
  - Advanced progressive Heart Disease (4)
  - Advanced progressive Neurodegenerative Disease (4)
- utilise an IPA approach to understanding the factors impacting on referral decision-making, also considering the impact of their personal and professional experiences
- explore the relationships between their perceptions of and attitudes to specialist palliative care and consequent referral practices
- identify the range of themes arising from each individual interview that may influence referral decision-making to SPCS
- group the individual themes and compare them with those of medical consultants working in the same speciality
- identify the similarities and differences in the themes across the three specialist groups
- locate the findings and debate them within the wider context of phenomenological, psychological, philosophical and linguistic theoretical frameworks to achieve more complete understanding

- develop and promote the use of IPA as a research approach of value in end of life care
- set the research findings within the local and national policy context.

### **4.3 RESEARCH DESIGN AND METHODS**

Phenomenology is the science of phenomena, of anything within the human world that can be either concrete or abstract. Phenomenological research seeks to provide a full description of lived experience and the life-world (see earlier in Chapter 3). It supports a deeper analysis of certain aspects of experience. It is derived from Husserl's approach to investigating 'the things themselves in their appearing' (Husserl 1998), the things being the experience of the individual living in the world. The focus of phenomenological research is the untainted experience which acknowledges the participants' individual voices. As discussed earlier this thesis requires and supports a more interpretative approach to exploring and understanding the consultants' experiences and thus privileged the IPA approach. The next section provides further justification as to the choice of the qualitative approach of IPA for this thesis.

#### **4.3.1 Interpretative Phenomenological Analysis (IPA) – a justification**

IPA emerged in the late twentieth century and is a contemporary research approach that resonates with the twenty-first century health care changes such as evidence based practice, clinical governance, user involvement and patient choice (Biggerstaff & Thompson 2008). Smith's (2004) reflective paper outlined that IPA was initially developed as a distinctive approach to research in health psychology before being adapted and adopted by many other professional groups to explore aspects of health care and professional practice.

IPA evolved from the inter-related strands of phenomenology (Giorgi and Giorgi 2008) and hermeneutics (Ashworth 2008) together with symbolic interactionism (Denzin & Lincoln 2000). These inform its approach. Phenomenology is Husserl's philosophical science of perception which

supports the exploration of how things appear to individuals and in their experience. It also includes how individuals perceive and talk about objects and events. Hermeneutics is the branch of philosophy that is concerned with the study and interpretation of human behaviour, structures of society, and how people function within these structures. Symbolic interactionism has, as its central concern, individual meanings which are only made accessible through an interpretative process that acknowledges the holistic complexity of the individual and their world. Thus IPA combines the idiographic approach with the interpretative activity of uncovering and interpreting meaning. It also locates the participants' personal and professional experience within their life-world as a means of helping achieve a greater understanding of their own and other human experiences.

The box below summarises the key features of IPA:

I = explores in detail participants personal experience and how they make sense of it , supporting 'good enough interpretation'  
P = focuses on personal lived experience, how the individual perceives objects/events  
A = provides the researcher with an analytical framework for making sense of the experience in helping the participant achieve understanding.  
(Smith et al 2009)

The way of asking research questions might provide clarity as to IPA's theoretical evolution and the specific approach it adopts. For example, phenomenology may ask, "*What is this kind of experience like?*", "*What does the experience mean*", "*How does the lived world present itself to me (or to the participant)?*" The challenge for phenomenological researchers is to help participants express their world as directly as possible. They also need to assist them in how to explain their experiences such that the lived world, their personal life world, is revealed (Finlay 2008). IPA moves their experiences forward through self-reflection and interpretation and thus the question might be, *How is it possible to gain access to and understand other humans' experiences?* (Dahlberg et al 2008; Smith et al 2009).

Thus IPA is a method of analysis rather than a philosophy (Smith 1996a). It has a clear theoretical foundation, flexible but detailed methodological procedures and an almost prescribed structure. For a novice researcher, it acts as both a signpost and reference point in ensuring the use of IPA is as consistent, congruent and robust as possible (Chapman & Smith 2002; Smith et al 2009).

At first sight IPA appeared to be an approach that was user friendly in its structured approach to managing data. Further exploration discovered it was more complex, requiring engagement with and understanding of both phenomenological theory and interpretation. The essence of IPA involves a 'double hermeneutic' or dual interpretative activity in which the participant is making sense of their personal, professional and social world, supported by the researcher trying to make sense of the participant trying to achieve that understanding.

IPA research also emphasises the role of the researcher in explicating the participants' experience and supports the active role of the researcher both in data collection and analysis. In the interviews the thoughts and feelings of the researcher are deemed an explicit and legitimate aspect of the process. It required development and engagement with a personal and professional self awareness which is demonstrated by self-disclosure and reflection throughout the research process - in particular, data collection and analysis. This is appropriate as its epistemology fits with my own clinical experiences (Elwyn & Gwyn 1999; Smith et al 2009). IPA's aim is achieved through interpretative activity on the part of the researcher and supports rather than negates their personal and professional interest (involvement, inclinations and predispositions) in these issues (Willig 2007). Conversely access to the participant's experience depends on, and is complicated by, the researcher's own conceptions and thus needs acknowledgement (Brocki & Wearden 2006).

This thesis evolved to fit with the requirements of IPA data collection in that it supported my personal involvement as a researcher and accessed, as

participants, a small purposive sample of participants working within a circumscribed geographical setting. Field notes and biographical details of the participants supported the audio recorded interviews and verbatim transcription (Wood & Ross-Kerr 2006).

Experience itself is the focus of this study – the experience of being a cardiologist, oncologist or old age psychiatrist, the experience of palliative care, the experience of being human – ‘a person’. The IPA approach supports attempts to elicit these multiple subjectivities in achieving understanding. It also seeks to discover what Willig describes as: ‘Dimensions of experiences which people find difficult to put into words and which seem to involve their entire being, in a pre-reflective kind of way’ (Willig 2007:209). In summary, as discussed earlier, IPA connects with the experiences, events and actions and the meanings they hold for participants (Chapman & Smith 2002). It is concerned with understanding what the respondent thinks or believes about the topic being explored. It is a data-driven (bottom-up) approach which prioritises participants’ accounts.

Brocki & Wearden’s (2006) critical evaluation of the use of IPA highlights certain requirements for its appropriate use. Firstly, IPA requires activity that moves the analysis beyond mere descriptive accounts. The structured analytical approach encourages use of the data that supports thinking about ideas and concepts, which will later inform the discussion. It employs interrogative skills with the requirement to ask questions especially closely and thoroughly as part of the interviews and as part of the analysis of the verbatim transcripts. Secondly, IPA supports inductive procedures in making sense of field data, which is similar to content analysis in uncovering embedded information and making it explicit, coding and categorising the individual, idiographic experience and then looking for similarities and differences and shared and unique themes between the participants. Finally IPA is about being open minded rather than ‘empty headed’ (Willig 2007).

Braun & Clarke (2006) in their critique of reductionist research methodologies, such as IPA, state that they are ‘theoretically bounded’. In the case of IPA,

bounded 'to a phenomenological epistemology, gives primacy to experience, is about understanding people's everyday experience of reality, in great detail, so as to gain an understanding of the phenomenon in question' (Braun & Clarke 2006:8). A further critique is that it stems from a particular, rather prescriptive theoretical and epistemological position that does not support variation in application 'in essence, one recipe guides analysis' (Braun & Clarke 2006:4). This is not my understanding, as IPA appears to support multiple perspectives.

Brocki & Wearden (2006) acknowledge that IPA is an applicable and useful approach in researching a wide variety of health topics but is often compromised by the lack of attention afforded to the interpretative elements. To ameliorate this criticism contemporary IPA research seeks to elicit the 'more' of the experience (Todres 2007; Todres & Galvin 2008) and supports increasing variation in thinking about analysis and in meaning making (interpretation) (Eatough & Smith 2006a; Eatough & Smith 2006b; Smith et al 2009).

A further reason for the choice of IPA lies in its flexibility in allowing for the unexpected in the participants' stories, experiences and their understanding. Approaches to data analysis support this flexibility by being three dimensional: descriptive, linguistic and conceptual (interpretative). This is supported by constant engagement with empathic reading of the transcripts and listening to the recorded interviews to achieve more complete understanding. Sense making is supported by speculative analysis which locates the themes to known work, theories or concepts as identified earlier in Chapters 2 and 3, which inform part of the discussion. The content of these earlier chapters were in outline and embryonic at the beginning of the thesis and were only rewritten after data collection and analysis had been completed, thus not prejudicing or biasing what emerged from the consultants' experiences.

I adapted IPA a little to make it fit for purpose, in this study the physicians are asked to reflect on and explore their *process* of decision-making rather than its *outcome*, by considering the factors and meanings that influence their

course of action or inaction (Smith et al 2009). The interviews focussed on significant issues (personal and professional) and perspectives that enabled a detailed exploration of the factors influencing consultants to refer or not refer their patients to SPCS. The interview account is jointly built by the participant and the researcher. Thus, this thesis is resonant with the idiographic requirements of the IPA approach in that it concentrates on specific individuals (medical consultants) as they deal with the situation of end of life care and the involvement of SPCS for their patient group. The IPA approach enables the identification of the shared experience of each consultant group before finally exploring the similarities and differences between the clinical specialities (Smith et al 2009).

#### **4.3.2 Why IPA in preference to other qualitative approaches?**

Mason (1996, 2002) suggests that qualitative research design offers far greater, theoretically informed, flexibility. Qualitative research inquiry is, by design, value bound being influenced by: the inquirer, the paradigm guiding the investigation, the context and the choice of theory to guide data collection and analysis. It seeks to explore the nature of reality, the ontological question. In this thesis there are likely to be many different constructed realities, exploration of which are likely to be divergent. This study seeks to understand the relationship between the knower and the known, they are potentially synergistic, interacting and influencing one another and informing the epistemological question and the consequent methodology.

The Critical Incident Technique (CIT) (Flanagan 1957) was considered at the outset as a possible approach to data collection as it is a familiar qualitative methodology, acceptable to doctors. It is a validated instrument with clear links to the professional development agenda and requirements for Continuing Professional Development (CPD). For this thesis it might have been appropriate as it uses factual accounts of actual events (incidents) in which the purpose and consequence of behaviour is clear – rather than generalisations or opinions (Bradley 1992; Allery et al 1997). Byrne (2001) identifies the common attribute of CIT in that it: ‘elicits aspects of best and worst practices’ (p538) often focussing on issues of discomfort and tension,

often describing incidents that did not go well. A criticism of CIT is that there can be a lack of clarity as to what counts as a critical incident (Bradbury-Jones & Tranter 2005).

For this research the CIT approach may have been helpful but also less flexible in that it was unlikely to support understanding of the more personal experiences of the participants which was an explicit and unique focus for the thesis. Interestingly, the open-ended interviews in this study elicited some CIT responses in relation to the participants reflecting on particular patient events, especially related to decisions being made not to refer patients to SPC services. CIT is implicitly present in the participants' stories. CIT embeds the responses in their actual professional practice giving a different but complementary voice.

Despite my rejection of it as the research methodology it is present as part of the conceptual framework, whereas IPA forms the narrative framework and takes centre stage in the analysis and discussion. IPA's idiographic focus enables a more personal accurate exploration of each consultant's perspective. It supports understanding and communication of the experiences of my participants.

The epistemological ideas presented in reflective life world research (also based on phenomenological philosophy) were used as an adjunct to IPA in this thesis as a way of understanding the consultants' experiences (Dahlberg, et al 2008). They support the importance of the life world and human intentionality as a way of enhancing understanding and acknowledge the importance of reflection in the process of achieving understanding. The experiences the consultants described were, as discussed earlier, critical incidents but their description of them appeared to be structured as a form of reflection. I also became aware that in the interviews my role as a researcher might be enhanced (or made worse) by my ability to reflect on my own clinical experiences. The caution being that although similar, my experiences were not those of a consultant and I have no direct experience in relation to referral decision making nor do I have overall clinical responsibility for patient care.



IPA and reflective life world research seek to ameliorate the historical disagreement which fundamentally separated or polarised the two traditions of phenomenology and hermeneutics (Dahlberg et al 2008; Smith 2008). The word approach used to describe both IPA and life world research is preferred to that of method, as method feels more prescriptive in conforming to a fixed set of rules whereas approach offers a more open and flexible interpretation. In trying to make sense of the consultants' worldview (life-world) it felt important to stay both with their description of experience and to make an attempt at interpreting it. Interpretation may be seen to violate the essence of phenomenology in reflecting the world as it appears to an individual but such interpretation is an essential requirement of IPA. The way things are experienced and understood is also made more accessible by the language used which is more fully explored in Chapter 11.

Paradoxically, the melding of IPA and life-world approaches in this thesis appears simultaneously congruent and incompatible. It is congruent in the sense that their joint focus of activity is phenomenological and seeks to understand the individual human experience within their life world. Incompatible in that IPA is a largely structured approach to exploring and analysing experience that acknowledges that the researcher has an active and intrinsic part to play in facilitating understanding of that experience. Whereas life-world approaches reflect the idea that the researcher is 'bridled' in that their experience, beliefs and values are suspended and do not influence the elucidation of understanding.

IPA offers a framework for deriving the data which suggests a phenomenological and interpretative approach to managing the data. The life-world approach offers fractions with which to explore the emerging data that supports phenomenological and interpretative approaches to analysis. IPA provides guidance in exploring both individual and shared experiences. Thus using IPA and reflective life world research approaches might support the achievement of the gestalt of the consultants' experience.

In summary:

- IPA is about valuing individuals' experiences
- IPA is interpretative in supporting participants to reflect on and interpret their experiences as part of the interview
- IPA interviews are systematically analysed on a participant-by-participant basis, that later supports comparison in this study between participants and across clinical specialities
- IPA supports interpretation of the consultants experience by undertaking descriptive, linguistic and conceptual analysis
- Doing IPA is a revelatory and creative process, the active interpretative role of the researcher is valued and as a novice researcher gives me both structure and freedom of thought and action (Larkin et al 2006)
- The complementary use of the reflective life world approach acknowledges the context in which the consultants work and enabled that to be reflected in their experiences and in achieving understanding

These factors support the appropriateness of both approaches for doctoral level study as described in this thesis

#### **4.4 ETHICAL APPROVAL AND ACCESSING PARTICIPANTS.**

##### **4.4.1 Research governance and ethical approval.**

The next part of this chapter includes an account of the specific research governance and ethical review processes and frameworks within which this study was undertaken. The steps supporting the ethical review and approval process can be found in Appendix 2.

The processes for Research Ethics Committee for Wales (MREC) and Trust Research and Development (R & D) site specific approval using the Integrated Research Application System (IRAS) are outlined but it focuses on the specific aspects which concerned MREC in relation to negotiating and achieving access to the participants who were busy medical consultants.

The research governance process was ensured by the gaining of external ethical approval, by completion and submission of the online Integrated

Research Application System (IRAS) documentation. IRAS supported the completion of multiple application forms for both the Wales NHS Research Ethics Committee (WREC) and the host organisations, the Local Health Board (LHB) and Research Review Service (R&D). WREC was chosen as it supported all Wales approval for the thesis, thus if recruitment was not successful in one LHB it would be an easier process to approach another site with All-Wales approval already being granted. The forms were submitted together with the study protocol (which included interview questions) and documentation (invitation letter [Appendix 3], participant information sheet [Appendix 4] and consent form [Appendix 5]).

Attendance at WREC was both a supportive and challenging experience, the committee expressed no concerns as to the ethical probity of the study and approved it unconditionally in September 2009 (Appendix 6). However in the discussion two members of the committee, both medical consultants, raised concerns as to its 'doability' and feasibility. They were uncertain as to whether busy physicians would be willing to give up their time to participate, especially as the study did not directly appear to benefit them or their patients. They also questioned how comfortable and responsive participants would be with the proposed open-ended interview structure and the personal nature of some of the questions.

These concerns lessened the relief of receiving unconditional approval and resulted in much discussion with my supervisor and the WREC co-ordinator. A reserve position was identified which would replace the proposed participant group of medical consultants by Clinical Nurse Specialists. Fortunately this was not required as the change of participants would have materially impacted on the study, its aim, innovative approach and the implications of what was discovered. The consultants were specifically selected as they are the 'gatekeepers' in helping or hindering access to other services.

The LHB R&D and Site Specific approval process was initiated in parallel with WREC. As a professional courtesy, and to support approval and access, the clinical directors from each speciality were approached via email explaining

the study and requesting their approval to establish contacts with the medical consultants working in their directorate. All responded and supported access, although one was concerned that the physicians' participation should take place as part of the working day and not intrude on their private time. This email correspondence was consistently copied to the LHB R&D team. Subsequent approval was received and accessing of participants and data collection commenced six months later in April 2010. The delay between obtaining ethical approval and data collection was related to personal events which necessitated a break in research activity.

Regular annual contact has been maintained with WREC through the annual report process and specifically the substantial amendments approval required in accessing old age psychiatrists as a further participant group and informing them of a change in academic supervisor. Annual contact has also been maintained with the LHB with completion of the annual review proforma and providing notification of the WREC substantial amendments proposal. Substantial amendments approval from WREC and R&D was obtained and the second stage of data collection commenced at the end of October 2010.

#### **4.4.2 Accessing and recruiting participants.**

R&D approval from the Local Health Board enabled negotiation and access to and selection of the study participants. The sample size needed was small, consistent with the requirements of IPA (Smith et al 2009) in providing a detailed account of an individual's experience, before extending the focus to the experience of a small number of homogenous participants, in first case cardiologists, the aim being to identify meaningful points of similarity and difference with them as individuals and as a group. As the intention of this study was comparative two further participant groups were selected oncologists and neurologists (the latter being replaced by old age psychiatrists).

On reflection there appeared to be two levels of gate-keeping that needed negotiation prior to accessing the participants. The Local Health Board (LHB) websites provided a list of medical consultants in speciality groups with details

of their areas of clinical responsibility together with secretarial contact details. Discussion of these lists with clinical colleagues was the first level of gate-keeping. It was undertaken to identify the consultants whose clinical role involved the care and management of individuals with life threatening conditions.

The cardiology and oncology consultants' secretaries provided the second level of gate-keeping, they either supported or acted as barriers to my establishing contact with the consultants with whom they worked. Initial contact with these individuals was made by telephone, followed by an email attaching the invitation letter and short participant information sheet. An identical but personalised email was also sent directly to the consultants. Further contact was maintained by telephone and for most it was possible to establish a working relationship, the majority of the secretaries had current and past personal experience of death or caring for a dying relative, they appeared keen to tell their stories. However these were private conversations and have not been used as part of this research.

Prior to the interviews, contact was made with the secretaries to confirm arrangements. All the cardiology and oncology secretaries were met face to face prior to the interviews, thanked for their help and emailed a few days later to reiterate my thanks. Four cardiology and four oncology consultants were recruited to the study.

On reflection, access to the neurologists, all of whom declined to participate, may have been influenced by the approach taken to their initial identification. The first two medical secretaries approached following my initial telephone conversation stated that their consultants 'did' palliative care well, were very busy and unlikely to have the time to be involved. Their prediction was proven as both the consultants declined to participate, asking their secretaries to communicate their refusal, so no direct contact was ever established. The influence of more senior colleague's refusal felt like 'reverse snowballing', which had a negative impact on recruitment. The other two secretaries who responded confirmed that one consultant had unexpectedly moved to England

to work and another consultant experienced a family bereavement during the recruitment time and access was not pursued.

As there was a much smaller pool of neurologists to choose from there were no reserves to approach. After discussion with my supervisor it was decided to access an alternative consultant group – old age psychiatrists. The rationale being that, for this thesis, a comparative exploration of the different specialist groups was proposed in order to understand the similarities and differences in their experience. As a group they were also chosen to reflect the current high profile of dementia in strategic end of life care documents. Thus the delay in data collection would be offset by the achievement of a more complete and contemporary context for the thesis.

This change involved the submission of a substantial amendments proposal to the Wales Research Ethics Committee (WREC) and the LHB Research and Development (R&D) Office. The process was onerous in the documentation required but approval to proceed took less than two months to achieve.

As for the other two participant groups, access to the old age psychiatrists was also facilitated by exploration of the website lists with clinical colleagues in order to identify the consultants whose clinical role involved the care and management of individuals with life threatening dementias. Four individuals were identified and approached, initial contact again being made through their secretaries. The two individuals who agreed to participate responded personally and made the arrangements themselves. I did not have contact with their secretaries other than the preliminary telephone conversation. It was decided however, due to practical and personal constraints, to access only the two psychiatry participants who had positively responded. This may have had some impact on their presence in the thesis, as they were a smaller number, but did enable their experiences to be acknowledged and their voice to be heard.

#### **4.4.3 Sample**

The final participants were selected utilising three approaches: identification of participants by clinical colleagues, snowballing via earlier participants supporting my contact with colleagues and opportunistically through my own contacts. A total of 10 participants were recruited for the study, this number being consistent with the requirements of interpretative phenomenological analysis (IPA) (Smith et al 1996; Smith et al 2009) which suggests a minimum of 6 being necessary to support internal comparison between groups. Small sample sizes are advocated because of the case-by-case, idiographic approach to analysis. The sample size of 10 in this thesis is supported by the richness of the individual cases, the approach proposed to compare or contrast cases and the pragmatic restrictions I was working with.

In this thesis participants were not selected to test a theory (Mason 1996) but they needed relevant experience in order to explore and describe the factors that may influence their referral decisions to specialist palliative care services, and be willing to consider and share their personal and professional perceptions, experiences and attitudes.

As discussed earlier the choice of medical consultants was made because they hold the clinical responsibility, power and decision-making autonomy and authority in relation to the care of their patients and generally facilitate (or not) referrals to other specialties (RCP 2007). It is also the participant group accessed by previous relevant studies (Johnson & Slalinka 1999; Friedman et al 2002; Johnson et al 2008).

The participant profiles are included in Chapters 7, 8 and 9 to give personal identity and professional background. I am aware that these more personal details may enable the individuals to be recognised, in particular by their peers, although I have consciously striven to protect their identity, but in the context of IPA this information feels apposite and relevant to include. The consultants' names have been changed to protect their identities and support confidentiality.

#### **4.4.4 Interviews**

The choice of the interview as the method of data collection was based on its prominence in qualitative research as a powerful tool in reflecting the participants' experience. It also appears to be the most common and is regarded as an exemplary way of collecting data in IPA research, although it is not an absolute requirement (Smith & Osborn 2008). The benefits relate to its flexibility in enabling the researcher to facilitate the participant in exploring what is unique and what they understand about their individual lived experience.

#### **4.4.5 The interview process**

After each participant had agreed to participate, I accessed information from the internet and relevant websites to determine their areas of interest other than their medical speciality. The aim of this approach was an attempt to relate to them as individuals as well as professional practitioners, if the interviews foundered it would establish a rapport. Before the interview proper and recording took place a short conversation usually took place as an attempt to break the ice and establish a relationship that might facilitate a more comfortable exchange. On many occasions this initial conversation was not related to work.

At the time of setting up the interviews but before recording, the participants were made aware that I was interested in *their* stories, of *their* experience together with the 'more' of *their* experience, in that there is always something more than words can say. I also acknowledged that there may be some experiences in the interviews that they (the participants) might struggle to give voice to (Holloway & Jefferson 2008).

The introductory letter outlined that consent to the recording of interviews was an essential requirement of the process. Prior to each interview that consent was formalised with one copy of the consent form being retained by each participant. Their involvement was predicated on the assurance that the interviews would not take more than an hour, all highlighted time constraints related to clinical and organisational demands as influencing this request.



Implicit in the interviews was the impression of reciprocity, the participants appeared interested in the research and felt that their contribution might be helpful in informing future practice. All the participants were happy to have their interviews recorded, most appearing familiar and comfortable with this, only two participants commented that they had not experienced this before.

IPA requires 'a verbatim record of the data collection event' (Smith et al 2009:73). It would have been impossible to do the form of interviewing required in this thesis and to explore the questions being asked without digitally recording the interaction. Making notes would have adversely impacted on the conversational, free-flowing and responsive approach that enabled the collection of rich data.

Recorded interviews supported my attempts to understand and identify the presence or absence of congruence between what respondents said, how they said it and how they behaved during the interaction. What was not identified in this process were my non-verbal behaviours and how these impacted on me, the interviewee and the interaction. I attempted to capture this by the use of reflective field notes, for example in the interview with one respondent when I became aware of my lack of specific knowledge in an aspect of dementia care related to the use of anxiolytics at the end of life.

The free approach, unencumbered by the need to write notes, enabled me to be more aware of the impact of the interview on the participant. It strengthened my awareness of their non-verbal behaviours, picking up on their discomfort with a particular line of questioning. For example one cardiologist was almost apologetic that his life had not been complicated by any personal experience of bereavement and loss, this was manifest by him getting more uncomfortable in his seat and avoiding eye contact; or the participant who was struggling with speaking due to her 'flu and recognising that she needed time out to cough and catch her breath.

Writing notes will have only captured a small part of the interview, most likely a particular fragment being recorded that felt important at the time or was

privileged by me. The recording and understanding of their whole experience would have been lost, the idiographic perspective being distorted or influenced by my agenda or by my unconscious and random note-taking which may or may not have been intelligible and comprehensible after the event. Note taking may have encapsulated the general idea but will have missed the fine distinctions and individuality of each participant's perspective.

Only one participant acknowledged the presence of the microphone during the interview as impacting on her responses in relation to the causative nature of smoking in relation to cancer. Other participants appeared only to be concerned with the practicalities and to check that the recording had been successful. Four participants unprompted stated that they would be happy to be recorded again, this confirmed to me that they were comfortable with the experience and is consistent with the practice of skilled IPA researchers as reported by Smith et al (2009).

Contemporaneous, reflective field notes were written to support the responses given during interview, this was done immediately afterwards. These acknowledged any conversations, comments and contextual information that occurred independently of the recording process. The discipline of writing these notes also supported my reflection on the interview experience and this additional data has proved useful in considering the embodied experience of the interview participant and interviewer, although this was perhaps initially paid scant attention. Within the interview it is possible to focus too much on words, ignoring bodily presence and action which may help in revealing the 'more' about the experience (Finlay 2006). Being sensitive to the bodily aspects of the interview was for me difficult, although I was aware of some mirroring of our body posture, of leaning forward when some particular points were being made and in two situations my participants almost moving backwards when personal issues were clearly troubling for them to discuss. These impressions were minimally acknowledged in my field notes and I am aware that I had not initially acknowledged it as a priority and I remain uncertain as to whether the gender of the participants may have had some impact on how embodiment was perceived.

All recordings were successfully completed, the environment where the interviews took place, the consultants private offices, enabled the recordings to be clear with minimal interruptions and extraneous noise. This clarity made transcription easier. The interviews were transcribed verbatim, including all the words spoken. As suggested, the level of transcription was undertaken at the 'semantic level' and included hesitations, pauses, over emphasised words, false starts and laughter (Bryman 2001; Willig 2007; Smith 2008; Willig & Stainton-Rogers 2008; Smith et al 2009).

#### **4.4.6 The interview questions.**

The inductive approach using open-ended questions (rather than hypotheses) sought to gain rich and detailed descriptions of the phenomenon being studied. The interview concentrated on each individual consultant, attempting to meticulously elicit and explore the factors impacting on their experiences. It sought to make sense of their experiences, specifically in relation to their understandings of palliative care and consequent referral practices.

This was enabled by the use of minimally structured interviews using open questions that were exploratory rather than explanatory. The interview itself attempted to facilitate some self-conscious phenomenological reflection by encouraging the participant to think about the experiences they were describing. The conversational style adopted aimed to encourage the individuals to speak personally about their experiences of palliative care services and end of life care for their patients, as well as covering the issues important for the thesis. Dexter (1970) and Burgess (1984) both describe this approach as 'conversations with a purpose'. For Kvale the interviews for this thesis therefore proceeded as a 'professional conversation' (Kvale 1996:5).

Alvesson (2010) illustrates the different purposes of the interview by the use of metaphor, describing it as either the instrument for data collection or the exercise of conversational skills. He cautions against according the interview a priori status, the researchers role being to 'think through a set of interpretive possibilities for assessing what the material is about and for what purposes it can be used' (p5).

To summarise, the questions were exploratory related to the process or experience of care and the participants' understanding of their clinical and personal experiences – 'its meaning'. They were 'phenomenal' interviews where both interviewer and respondent are caring companions with a commitment to empathic search (Lincoln & Guba 1985:269).

The interview, with its questions, prompts and enablers, was focussed on trying to get as close as possible to the participants' experience and to enable the participants to get close to their own experience. Their descriptive comments of concrete embedded experience gave a sense of the 'why'; I attempted to explore the 'what' and 'how' which saw a revisiting of the experience to focus on what was important to them. There was a conscious attempt to work with participants enabling them to try and put their experience into words, this was at times difficult for them and the use of metaphor and imagery made it easier. There were many perspectives to their stories that were at times contradictory and ambiguous and the task was to elicit the entirety of their 'life world', leaving me the role as an enabler to the illumination and reflection of their experience (Dahlberg et al 2008). As Kvale (1996) describes an interview 'is literally an inter view, an inter change of views between two persons conversing about a theme of mutual interest' (p.2).

The interviews were conducted as a particular form of conversation characterised by careful questioning and listening, intensely idiographic and mutual with a meandering style that facilitated the potentialities of meaning. Kvale (1996) describes two contrasting metaphors of the interviewer as either a miner (where knowledge is a given) or traveller. The traveller metaphor appears appropriate for this IPA study as it supports post-positivist constructive understanding of a conversational approach to health and social care related research and its subsequent interpretation. The interviewer is a traveller who:

wanders along with the local inhabitants, asks questions that lead the subjects to tell their own stories of their lived world, and converses with them in the original Latin

meaning of conversation as 'wandering together with' (Kvale 1996).

The process for both myself and the consultants involved the learning of new routes, the taking of many wrong turnings and reaching dead ends. There were stages in the journey where travel was slow and at other times when the traffic was more free-flowing. Thus in IPA, the participants are seen as fellow travellers, experiential experts and story tellers rather than respondents (Virginia Eatough 2011, IPA Masterclass).

The interview is consistent with the biographical interpretive method and supports the proposed analytical approach. The schedule for the interviews was semi-structured or, more accurately, minimally structured, the purpose being to guide the process and to ensure a degree of consistency between the interviews. The schedule was useful in providing a script to follow, learning to be flexible and go with the flow of the participants' story and experience took adjustment and some courage. I was aware their experience was central but, going with their story, their personal experience was compromised by my perceived need to do it correctly, to collect material relevant to the research questions and my own uncertainties as a neophyte researcher where the script provided a framework. In the later interviews my minimally structured interviews were there but the approach was more iterative in that I learnt to follow the responses to the first question by more spontaneous and individualised probing. The interviews were undertaken as real-time interactions that were perhaps initially compromised by lack of opportunity for reflection and time to think, especially about sensitive and difficult experiences.

The approach was non-interventionist, demonstrated by generally using open questions supported by gentle probing which supports exploration of 'a broad topic and for focusing in greater detail on particular issues' (Glynn-Owens & Payne cited in Murray & Chamberlain 1999:151).

The interview questions were derived from a preliminary literature review, discussion with my supervisors and my clinical and personal experiences. The interview questions and prompts sought to explore the individual (idiographic) perspective in relation to their:

- Involvement with palliative care services
- Perceptions of palliative care services for their patient group
- Motivators to refer
- Difficulties in referring
- Personal experiences
- Ideas regarding future service developments

The different types of questions used to structure the interviews were:

Descriptive – “Please describe how you use palliative care services for your patient group”?

Narrative – “Can you tell me about how you might go about making a referral”?

Evaluative – “How do you think your personal experiences influence your professional role”?

Comparative – “How does your patient group compare with [*type of*] patients”?

All the questions were supported by prompts and probes to encourage and clarify responses.

These differing approaches were designed to support the more conversational style. The interview moved from scene setting, the less personal, by a process of ‘funnelling’ to more sensitive topics. deMarrais (2004) elucidates this approach by the use of metaphor in likening the interview to ‘going out to dinner with a close friend who has been away for a long time’ (p63). The interaction includes preparation and planning for the evening, the transition from lighter to increasingly personal elements in the conversation and prior to the end of the meal a return to lighter topics, it concludes with plans to keep in contact.

The participant responses influenced the rhythm and dynamic of the interaction, on reflection each interview was unique and subtly different in style and pace, reflecting the individual approach. Ben's interview was fast, it contained quite clipped responses and was the shortest. Had this interview not been the second one undertaken I may have been more comfortable in attempting to slow the interview and encourage a more revelatory interaction. Ian's interview, the second to last, was by contrast slower and I am aware that I stayed with his experience more closely despite the fact that we went off track, as a consequence I was able to understand his experience more fully. Most of the other interviews appeared more gentle, relaxed and longer.

The interview required the consultants to explore and reflect on their past experiences both personal and professional. It was clear that their memories were fallible and may have been influenced by their current situation, the time elapsed since that particular experience, suggestions on my part (for example in predicating the question about their personal experience of death and dying as being possibly the most difficult one in the interview) and their present mood and morale. The importance of exploration of past events was to enable the consultants to reflect on their past experience, consider the meaning of that experience and locate the meaning of that past experience in their current practice. This was helpful in particular for those participants who had experienced the loss of a close family member and reflected on the impact this experience had on their current professional role. Interestingly there was no shared meaning, each used the experience uniquely, either to inform their practice or not explicitly acknowledge it as influencing their professional lives.

Being physically present and actively involved in the interviews enabled me to see as well as hear (Mason 2002). The benefits being a more 'present' and responsive dialogue. The contemporaneous field notes informed data analysis by acknowledging the context, the non-verbal and other aspects of the encounter.

#### **4.4.7 Researcher involvement.**

IPA relies on the double hermeneutic (dual interpretation process) that access to the participant's experience depends on, and is helped and hindered by the researcher's own conceptions,

the participants are trying to make sense of their world;  
the researcher is trying to make sense of the participants  
trying to make sense of their world (Smith & Osborn  
2008:51).

Reflexivity demanded acknowledgement of my perspectives in that the meanings derived from the interviews are potentially contestable and personal. Interviews themselves are usually dominated by 'options and potentials' with 'limits and shortcomings' being marginalised in the interview question and subsequent prompts and probing. I attempted to ameliorate this perceived preference by exploring with the participants the advantages and disadvantages of palliative care referral for their patient groups and their personal perspectives. The issue of reflexivity and openness as a measure of quality is explored further in Chapter 12.

Alvesson (2010) suggests researcher reflexivity should pragmatically encompass a 'critical consciousness of the problems of interviewing' (p7) by adopting a less naïve and more creative approach. The success of the interview approach was dependent on the participant's willingness and ability to engage, verbalise, recall and reciprocate. The interaction between us was facilitated by my role as a researcher, being active and reflexive. Building on the interactive, conversational, ontological approach by asking questions, listening to and exploring their responses and attempting to construct and reconstruct their experiences and understandings. The purpose was to gain a detailed and extensive account of their experiences. Kvale (1996) summarises the use of interviews as producing accounts that 'obtain descriptions of the life-world of the interviewee with respect to interpreting the meaning of the described phenomena' (p5-6).

The intent of the interview was to use a number of minimally structured questions, in reality as I became more confident there were fewer questions



and more probes, prompts and enablers. As the interviews progressed I became more comfortable with probing and questioning their responses as a way of obtaining more in depth perspectives. Consequently, the interview times increased as the study progressed, except for the last interview with Mair which was shortened as a result of her 'flu and hoarse voice. Despite my feelings of being more questioning during the later interviews, on listening to the digital recordings they contained much less of my voice and more of the participant's voice.

At the end of each interview, after the tape recorder had been turned off, a short debrief occurred with agreement made for further contact by email. Many of these conversations included reference to achieving balance in personal and professional lives. A number of the participants commented on the value of considering what had happened to them as people and how this impacted on them as professionals. They were surprised, but not uncomfortable with the more personal questions, none refused to answer. This interaction yielded important information and the participants agreed that this would constitute data for the thesis. It was captured in my contemporaneous reflective field notes.

#### **4.4.8 Practicalities.**

The interviews were recorded using an MP3 digital recorder, using a lapel microphone, audio recording being a pragmatic, 'unimpeachable data source' (Smith 2008). The interviews were directly downloaded to the computer hard drive for listening and verbatim transcribing. Field notes (as discussed earlier in the chapter) were made immediately after each interview to reflect on the process and my experiences.

The interviews with the cardiologists were recorded and transcribed in sequence during April and May 2010 all being completed prior to the interviews with the oncologists, again these were conducted and transcribed in sequence during June and July 2010. As discussed previously, the non-participation of the neurologists necessitated a gap in the interview cycle as the psychiatrists involvement was subject to substantial amendments ethical

approval by the Wales Research Ethics Committee (WREC) and the ULHB Research and Development (R&D) Office. The subsequent interviews with the old age psychiatrists took place in November, two months after the death of my father. I am unsure as to whether or how much his death impacted on the last two interviews, but perhaps subconsciously I might have been more guarded and self protective, avoiding the more deeply personal. Listening to the recordings does not confirm this was the case. Recruitment, data collection and transcription therefore took place over a period of almost nine months.

#### **4.4.9 Conclusion**

I am aware that I have been fortunate in being able to interview 10 consultant colleagues. WREC were sceptical as to whether any would agree to participate, have the time to be involved and be prepared to disclose personal information. The interviews felt reciprocal and supported a mutually beneficial exchange. None made me feel intrusive and there was no evidence of a power imbalance between myself as a nurse and them as physicians, this was unlikely as in this study a nurse was the researcher and a consultant physician the respondent, thus the existing power balance was likely to be in favour of the research participant. I did not feel in any way overawed by their position or expert knowledge except on one occasion. The majority of consultants interviewed were men, reflecting the gender balance in medicine at consultant level, for me there was no overt acknowledgement of gender impacting on the process.

All appeared to embrace this minimally structured qualitative interview approach, acknowledged the importance of care at the end of life but recognised dying as integral to life. None abdicated responsibility for care of their patients who were dying, most however put it into perspective identifying that it was *not* the most stressful part of their professional lives.

All replied to my 'thank you' emails and offered further help if needed. All except those about to retire were interested in hearing the outcomes of the

research and how it might impact on practice. This I agreed to do on completion of the thesis.

Part 2 of the thesis concentrates on the participants' experience. Chapter 5 specifically describes the process of data management. It presents a linking of analytical methods and findings in supporting understanding of the consultants' individual and shared experiences. The discussion section is not presented in the traditional IPA way of melding descriptive and conceptual data analysis. The approach adopted was intuitive emerging from the consultants, stories, it just felt right. By splitting the descriptive and interpretative analysis there was a sense of being more likely to privilege the individual participants' voices thus supporting the primacy in IPA of the idiographic approach. This was additionally helpful as the cardiologists and oncologists were particularly homogenous groups.

## **PART 2: THE PARTICIPANTS' EXPERIENCE.**

### **CHAPTER 5 - DATA MANAGEMENT, ANALYSIS AND REFLECTION**

**If my heart could do my thinking, and my head begin  
to feel,  
I would look upon the world anew, and know what's  
truly real.  
(Van Morrison 1987).**

#### **5.1 INTRODUCTION**

In IPA, the aim of data analysis is to get as close as possible to the participants' experience. It supports an idiographic, phenomenological and interpretative approach to data analysis which legitimises the use of first person accounts as data (Larkin et al 2006). Therefore this chapter seeks to present and describe the participants' experience by the balanced use of both the phenomenological and interpretative elements. The chapter will consider the activities and approaches associated with descriptive and conceptual data analysis. It will be presented in a way that interweaves analytical method and findings which appears consistent with the complexities of IPA. Linguistic analysis and discussion will be presented separately in Chapter 11.

In dealing with the large amounts of data produced by the 10 interviews, three tiers or levels of analysis were undertaken (Eatough & Smith cited in Willig & Stainton-Rogers 2008). This supports a 'funnelling down' approach. These three tiers were identified following personal discussion with Virginia Eatough as part of an IPA Masterclass (April 2011).

- Idiographic and biographical.
- Cohort level; explicating a descriptive, shared narrative by undertaking a broad thematic analysis and low level interpretation.
- Hermeneutic experiential detailed analysis of a significant event in a particular rich case(s).

This approach was adopted for pragmatic reasons, but still supported acknowledgement of the commitment to the case study level of analysis, and the need to compare or contrast cases and to value the richness of particular individual experiences.

## **5.2 - DESCRIPTIVE DATA ANALYSIS**

### **5.2.1 Overview**

Initially the content of the interviews was described. The understanding of the individual experience was derived by the identification of key words, phrases and stories that appeared to matter to each of them. The issues that mattered to each participant were initially outlined without interpretation, accepted at 'face value' and supporting the phenomenological element of IPA. These issues are presented as descriptions, beliefs, ideas, quotes, metaphor, language, paralanguage and emotional responses. My aim was to identify aspects which contributed to, and influenced each, participant's thoughts and experiences. This part of analysis deals with the uniqueness of individual experience. Following the initial identification of themes from the transcripts, the tables were constructed and then the responses of each of the participants for each of the groups were described (in Chapters 6-8) using the tables as a template.

The participants were all given alphabetical pseudonyms (except Mair for whom a name starting with J just did not seem to fit), to preserve their anonymity. Their interview narratives were presented with hesitations and paralanguage removed but otherwise were unadulterated. The purpose was to improve and support sense making.

### **5.2.2 Descriptive analysis – the process**

Authors such as Braun & Clarke (2006), despite criticising IPA for its 'cook book' approach, identified methodological guidelines using a six step approach to support thematic analysis: familiarising yourself with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and subsequently producing the report. This thematic style of analysis is congruent with the framework proposed by Smith et al (2009), for single cases he describes 'familiarisation with the data, identifying themes, clustering themes and constructing a summary table', the further stage of 'integrating themes' is proposed for multiple case analysis. This thematic approach is in contrast to Giorgi's descriptive phenomenology (Giorgi & Giorgi 2008) in that it is logical, structured and focussed on each participant's

experience. What is unique in IPA is the double hermeneutic, the interpretive aspect of IPA, the way it deals with the data in its idiographic approach that does not rely on paradigm cases, together with the sharing between the participant and the researcher.

The following describes the in-depth process of descriptive data analysis undertaken in this thesis. The first step involved reading and re-reading the transcripts and listening and re-listening to the audio recordings. The purpose being to fully engage with the data, making the participants' stories live and be part of my consciousness.

Willig (2007) made an important point that was helpful for me to be aware of before undertaking data analysis, that being 'the interview transcript may tell us about how the person talks about their experience, how they describe it, how they construct it – it may not be about the experience itself' (p 63). This sensitised me to be alert to the possibility of their experience being an artefact or mediated by the professional context. From a criminology and psychoanalytical perspective the free association narrative method was considered during the analytical process as it is used exploring the responses of well defended participants. A few of the medical consultants Ben, Flynn and Mair appeared constrained when interviewed, their responses being at times guarded and fragmented. In the description of their experiences their reality is perhaps more likely to be hidden (Holloway & Jefferson 2008).

I chose to work exclusively with hard copy material of all 10 interview transcripts and not to use a software package to support data analysis as it does not fit comfortably with my usual working practices or what appeared to be IPA's core ideals as evidenced in the literature. On a practical level, for a less than skilled computer user, it felt cumbersome and the time taken to potentially familiarise myself with it would be precious time wasted. It was also a more personally comfortable approach. The value of this 'atechnical' approach was the personal and close relationship that was established and maintained with the 'actual' participants stories.

The process undertaken was iterative and inductive requiring a meticulous line by line analysis of each individual transcript with each participant being treated as a single case, the purpose being to understand their lived experience. It was very time consuming. The benefit was that I became very familiar with each transcript and its content.

For the first participant group, the cardiologists, hard copies of each of the interview transcripts were printed and used as the basis to facilitate analysis. Initially, each individual transcript was formatted with a small margin on the left hand side for initial comments and a wider margin on the right hand side for annotation, comments and early identification of key points.

Alex's transcript was printed, analysed independently and annotated with colours to identify his descriptive (blue), exploratory (green) and linguistic (red) comments. Direct quotes that were identified as reflecting important individual points of richness or that might be used in the writing up because they encapsulated important issues in the analysis, were highlighted and recorded alongside the field notes and biographical details in my research notebook. Each of Alex's comments, again using the same colour coding, were written on post-it notes that were then stuck randomly to large sheets of flip chart paper. The use of post-it notes enabled the comments to be visually scanned and then moved on the paper and grouped together into common themes. This idiographic case by case approach to analysis enabled me to make specific statements about each individual by focussing on their particular experience.

It was a very laborious but scrupulous process and was supported by listening to their interviews in tandem with the post-it note activity. This supported audio and visual approaches in an attempt to ensure congruence in analysis. The same approach was employed to working with the transcripts of the interviews from Ben, Chris and Dan. (Appendix 7 shows a scanned picture of the post-its and flip chart). The post-it notes were coded with the same colours for each of the subsequent participants and ascribed a number so the individual was identifiable e.g. Alex = 1, Ben = 2, Chris = 3, Dan = 4. The

comments from each of the other three cardiologists were grouped together, linked and compared with the themes derived from Alex's interview. Individual themes, concepts and thoughts were then considered in the light of the responses of the rest of the group, looking for emergent patterns and connections that supported the shared experience of the group.

The identification of shared experiences worked in a slightly back to front way for me, in that it enabled identification of each participant's unique story experience by the process of elimination. Grouping together of common experiences left behind what was unique. Any unique or previously unidentified themes were also stuck to the flip charts for exploration as part of the following chapter which focussed on the participants' individual experience.

As a final check the original audio recordings were then re-listened to and the transcripts revisited to ensure the themes identified as part of this analytical process were present in the cardiologists' stories.

A more interrogative and curious approach to the content focussed on exploring the specific use of language, which was supported by attempts at deconstruction providing a detailed focus on words and meanings. The linguistic comments were kept separate as, at an early stage, I recognised that these elements of the interviews were unique and worthy of particular attention. Highlighter pens identified the specific use of language, for example metaphors and binary opposites (see Chapter 11).

The initial list of themes emerged chronologically in order of appearance in the transcripts, this may have related to my interview approach with the cardiologists which was more structured in approach, reflecting my uncertainty as a researcher and lack of familiarity with IPA. These themes were further explored by the processes outlined by Smith et al (2009) to establish connections and patterns within the three groups. These processes were abstraction, subsumption, polarisation, contextualisation, numeration and function enabling a deeper understanding and immersion with the data.



The descriptive discussion presented in Chapters 6, 7 and 8 will reflect the structural themes present in the literature review: historical and political background, clinical diagnosis, disease trajectories, prognostication, patient perspectives, physician perceptions and models of service delivery. The literature review, as stated previously, was completed retrospectively following data analysis and informed and was informed by the discussion.

The tables have been constructed to include direct quotations from the participants (in italics). Their comments have also been rephrased, précised and paraphrased to facilitate tabulation and presentation in the text (Chapters 6 to 8) but have not been interpreted or changed in any other way.

## **5.3 DESCRIPTIVE DATA ANALYSIS – THE FINDINGS**

### **5.3.1 The cardiologists**

In the descriptive analysis, the shared approach appeared to work because they were the most homogenous group of participants. The subordinate themes derived reflect the experience of all the cardiologists and were related to:

- Patterns of Referral (includes past patterns and extrinsic factors impacting on referral practice)
- Perceptions of palliative care
- Complexities of decision-making
- Resourcing
- Specialist knowledge
- Personal experience
- Models of service delivery
- Nurses

These may not all be easily recognised as themes, they may be more easily identified as topics, ideas, concepts, terms, phrases and keywords.

The following table provides more detailed descriptive accounts from each of the cardiologists that illustrate and support the superordinate themes emerging from their experiences.

**CARDIOLOGISTS: Alex, Ben, Chris and Dan.**

**Theme: Patterns of Referral**

ALEX	
	Not actually referred for palliative care
	Timing
	Co-morbidities
	Perceived coping
	Psychological impact
	Internal within team
	Risks of referral
	Should refer more
	Family request active seeking of help
BEN	
	I do that <i>[refer]</i> infrequently
	Changing care focus and goals
	Family structures support or deny care
CHRIS	
	I have referred <i>[reflects on one particular example]</i>
	When no conventional options left
	At the very end
	HF patients highly selected for referral
	Family led /involved
	Only used for the <i>'tip of the pyramid'</i>
	Quick access to particular aspects of care
DAN	
	A quick answer is yes, <i>[reflects on one particular historical example that went well, currently more problematic]</i>
	Often related to family factors
	Relevant for articulate communicating and coping families.

### Theme: Perceptions of palliative care

ALEX	
	Holistic care
	Cancer focus
BEN	
	Cancer equates with symptom control
	3 areas of intervention Analgesics, sedatives and anti-anxiety
	Cancer prognostication straightforward
	Inequity of access
	Environment of care
CHRIS	
	Holistic support
	Increase quality of life
	Associated with cancer and death
	Place
	Historical association with cancer
DAN	
	Experience related to care in the community
	Cancer centric
	Support to care givers at home.

### Theme: Complexities of Decision- making

ALEX	
	Decision making is 'tricky'
	Continuing therapy versus admitting defeat
	Difficulties relating to transitions between cardiology and palliative care
BEN	
	Difficulties re: decision-making
	Choices patient/ personal
	Choices aggressive/palliative
	Alternative perspective has some value
	Patient -led

CHRIS	
	Difficult to be objective
	Evolutionary nature of decision-making
	Personal perspectives: ' <i>Grandmother/father test</i> '
DAN	
	Complex at the end of life especially with regard to plans for care
	Care pathway facilitates decision that the person has reached the end
	Usually decision follows the patients own thought
	Seamless transitions the ideal

### Theme: Resourcing

ALEX	
	Inequalities of provision
	Inequities in provision
BEN	
	Inadequate resources
	Priorities for clinical activity
	Resource limitations
	Finite/negative resources
	Pragmatic service delivery
	Management of personal workload
	Economic constraints: Macro/meso level
	Reallocation of resources
CHRIS	
	Service availability limited
	Models of service at different levels
	Resources limited
	Poor communication between providers
	Poor coordination between primary, secondary and tertiary care
	Place of care may be dependent and may change with the trajectory
	HF resources limited e.g. no HF nurses

	HF poor current service provision
DAN	
	Inequity in access non-cancer
	Inadequate and finite resources

### Theme: Specialist Heart Failure Knowledge

ALEX	
	Patients awareness not terminal
	Cardiology is reductionist (Medical & device therapy)
	Difficulty with HF nomenclature
	Always something you can do
	Palliative care may not have knowledge regarding HF
	HF many co-morbidities
	HF reduced quality of life
	HF uncertain disease progression
	HF end stage and deterioration unpredictable
BEN	
	HF focus on active treatment
	Palliative care in HF is ' <i>a message of surprise</i> '
	Knowledge and experience HF and palliative care
	HF knowledge and awareness helps coping
	HF patients want to live as long as possible
	Less public understanding of HF
	HF unpredictable
	Cardiology deals with causes rather than symptoms
	HF palliative care is unique
	HF trajectory complex
	HF focus on active treatment
CHRIS	
	Must get other bits of care right as well
	HF patients good awareness
	HF lots of therapeutic options

	HF prognostic uncertainty
	HF is a chronic disease
	HF ' <i>up and down trajectory</i> '
	HF language is emotive
	Its all about knowledge of trajectories and transitions
DAN	
	HF cardiology makes better but not always
	Death inevitable
	HF sudden death is positive
	HF prolonged death is negative
	A good death is the expected norm in society
	Information giving on diagnosis always highlights reduced life expectancy
	HF unpredictable disease pattern
	HF co-morbidities ' <i>tip them over the top very quickly</i> '
	HF difficulties re: diagnosing dying
	HF disaster if patient dies in A&E
	<i>Internal</i> team working very important
	Disease transitions tricky.

### Theme: Personal experiences and reflections

ALEX	
	Difficult to admit defeat and handover care
	My clinical role characterised by ' <i>pessimism versus optimism</i> '
	Pulling back active/passive involvement
BEN	
	Role characterised by personal and professional anxiety
	No personal experience of death and dying
	Only offer a work-based perspective
	Only experience was palliative care in training
CHRIS	
	Mother died from a brain tumour very different from HF
	Personal experience leads to a value judgement of the impact of palliative care

	Palliative care accelerated mothers demise (appropriately)
	<i>'I have a medicalised view of the world – that mothers dying was not prolonged'</i>
	Personally rare as a consultant for me to initiate end of life discussions regarding additional support – nurses more likely to
	Personally <i>'death denying, wanting to die as late as possible'</i>
DAN	
	Personal experience from initial training – was encouraged to hear patients stories related to their death and dying
	Reflecting on this was good preparation for care of the dying
	Reflects on the importance of experience
	Personally <i>'look on the bright side'</i>
	Personal issues related to fears of death and mode of death (believes this is also the issue for patients and families)

### Theme: Models of service delivery

ALEX	
	Pathways give guidance
	Shared approach
	Shared care
	Unique and overlapping competencies between both specialities
BEN	
	Guidelines support models of service delivery
	Best practice exemplar is shared care
CHRIS	
	HF and palliative care should be a consultation service
	Palliative care should not be managers of care
	Access to services should consider the broader impact of disease on the family and society
	Models of care should enable dip in and dip out
	Pathways for care 80% good: 20% poor – poor usually relates to coordination of care
DAN	
	Access to palliative care but still keep patients <i>'get in-pull out'</i>
	Best outcome is the best mode of death, best managed death
	<i>About</i> advanced care planning

	Care pathway is a framework for care, not fixed but flexible
	Ideal is to follow own patients through

### Theme: Nurses

ALEX *	
	Nursing role is the bridge of care
BEN *	
	Heart failure nurse are the bridge
CHRIS *	
	Palliative care is the HF nurses role
DAN	
	Heart failure nurses are positive
	HF nurses balancing demands and time on the newly diagnosed patients and those at end of life
	HF nurses present during the end or palliative phase is when the family needs most acute
	Benefits of having a palliative care regional HF nurse would be resource effective in relation to workload issues.

Alex, Ben and Chris' services do not have access to heart failure clinical nurse specialists (CNS's) as part of their team. Therefore their responses are largely theoretical as to the perceived benefits. They have as a team approached the British Heart Foundation (BHF) for external funding. There are a number of UK projects where the BHF fund regional heart failure/palliative care CNS's, the funding is contingent on the local providers agreeing to the future funding of the posts after a circumscribed pump-priming funding of between 3-5 years. Their Local Health Board have not yet supported this service development.

### 5.3.2 The oncologists

The same exploration of the individual experience derived from each interview was subsequently undertaken for Eve, Flynn, Greg and Hermione. As the data analysis progressed it was clear that I was becoming more confident and competent and my dependence on these steps lessened, they became more



of a framework. When the process became particularly difficult these steps acted as a 'safety net' or a reference point.

For analysis of the interviews with the oncologists and old age psychiatrists the *post-it approach* was modified. Each interview transcript was, as before, annotated with comments in both margins to aid identification of themes and key points (topics, ideas, concepts, terms, phrases and keywords). Potential verbatim quotes and linguistic elements were again identified by highlighter pen. Each of the participants' responses were then categorised under emerging headings in my research notebook and then tabulated enabling the identification of shared and individual themes across each of the two groups. The themes from the cardiology interviews were used as a template.

The following list of themes for the oncologists was reflected in each of their interviews:

- Patterns of Referral (includes past patterns and extrinsic factors impacting on referral practice)
- Perceptions of palliative care
- Specialist knowledge
- Complexities of decision-making
- Resourcing
- Personal experience
- Models of service delivery

These shared themes were reflective of their shared experience and understanding as a group; the only missing theme was that they did not, as a group, explore or focus on the role of nurses. There was no explicit mention of the role or need for nurses from within the oncology participant group, this may relate to their familiarity with and the large number of CNS's working in oncology and palliative care settings. In Wales there are approximately 200 oncology CNS's, (this number excludes palliative care CNS's who often have a dual role) as opposed to 27 working in Heart Failure (Personal Communication Liz Gould Cardiac Network WG 2011).

The following table provides more detailed descriptive accounts from each of the oncologists that again illustrate and support the superordinate themes emerging from their experiences.

## **ONCOLOGISTS Eve, Flynn, Greg and Hermione**

### **Theme: Patterns of Referral**

EVE	
	Yes, frequently
	On an outpatient basis due to ease of access, usually the Macmillan nurse
	For increasing physical/psychological symptoms
	Negatives of referral possible bad experiences nurses always talking about death
	More likely to refer if relationship with the palliative care team
	Many patients not seen by oncologists – directly referred without me knowing
	Referring less ?already referred or just one of those things
	Less used for physical symptoms more for 'putting things in order' or for coping
FLYNN	
	Yes, often
	Integral part of patient management/cancer management
	For difficult symptoms
	Patients may read it the wrong way – my job to disabuse
	Ideal is to refer before a 'crunch point' – proactive planning
	Improves quality of life
	Easily available and accessible (except geographical issues)
	When advanced disease and symptom problems but otherwise mobile
	Support for family
	Enable establishing of a relationship
	Anticipate needs
	Not radically curable patients
	Dual diagnosis; multiple pathology; co-morbidities
	Physical and psychological problems
	After an acute event

	Support adaptation from curative to terminal but not just palliative care
	Change in outlook/approach
	In early cancer treatment – for symptoms associated with treatment; dysfunction and chronic pain; for advice and support
GREG	
	Yes, several times a week
	Types of services inpatient and community
	Reasons for inpatient advice re: symptom control e.g. pain, dysphagia, discomfort and anxiety
	Aim to get home (not always)
	Hospice refer cancer patients back for active <i>cancer</i> treatment
	Don't take people with a chronic condition
	Geography of unit problematic and have to live with it – affects how patients view it
	I achieve a collaborative role/relationship between oncology and palliative care ?seen as a threat
	Refer earlier for symptoms less likely to be refused
	Relatives put a 'bar' do not encourage often refuse referral 'Mum will know she is dying' – explain to them that Mum knows, it's you who hasn't accepted it
	Many doctors resist referral, should refer earlier
	I refer too early
	Refer for relatives' needs not always patients needs: children, bereavement, support, negotiation
HERMIONE	
	Yes lots and lots
	Early in disease, when still currently well
	Involved early
	Symptoms but not terminal
	Early to build a relationship or at a stage where no further active treatment
	Symptoms from cancer or from cancer treatments
	Psychological support
	Family support
	Day care
	People with young family and children (facilitate good and bad memories)

	Husband not coping with wife's diagnosis
	'Safety net'
	Family encouragers – isolation, need for help, avoid family panic, 1 <sup>st</sup> point of contact
	Small number resist palliative care

### Theme: Perceptions of palliative care

EVE	
	Care at home, problems at home, reality of their situation often associated with poor mobility and difficulties with the home environment
	Hospice care is peaceful, appropriate medication
	Place of care patients at home different from patients in hospital
	In relation to other patient groups. Different disease, different trajectories, nursing rather than medical care
	End stage HF has a long terminal phase
	Good death depends on: carers and place of care
	Does not always have the answers
FLYNN	
	Community services 'better access to patients realities of daily living'
	Hospice for terminal care, hospice is respite, hospice is rehabilitation
	Palliative care is a place of care, variety of places
	Experts
	Conducive environment
	Holistic
	Some oncologists hold a negative view of palliative care
	Patient perceptions: hospice is death, word hospice is a 'big block', historically negatively associated with cancer care, going to die, one way ticket.
	Some patients never heard of it.
	Perceptions are changing but slowly
GREG	
	Advantages intensive assessment of symptoms
	Seamless care
	Shared care

	Holistic
	Integrated
	Care of the patient in their environment, not just the family
	Palliative care could not exist without oncologists
	Different specialities and ambitions, lots of 'empire builders' in palliative care
	Patients view hospices as a place to die
	In the past palliative care viewed with antagonism and suspicion by oncologists
	In the present it has 'grown like Topsy'
	'safety net' for patients
	As an oncologist not sure what palliative care wants from us
	Palliative care now uncertain as to where they fit, what patients they take 'oscillating like a pendulum'
	People always go to the death section in the local paper, deaths in the hospice colours their views leading to resistance
	Patients feel oncologists won't see them when there is no more active treatment
HERMIONE	
	Palliative care makes my life easier
	'safety net' gives my patients a bit of control when it can't be me; at home lessens panic about who to contact/where to go
	'go between' between patient and GP, patient and hospital
	Facilitates a better death
	Facilitates symptoms and a 'good death'
	Supports decisions re: place of care
	Dying at home, done properly is hard work
	Misconception that palliative care is end of life treatment only
	Nomenclature a negative/disadvantage
	Symptom control and dying
	Hospice is end, 'see the fear on their face'
	Morphine, dying, last resort and 'end of the road'
	Patient and family experience: when the patient has died it is poor memories that stay with you not the good times
	Good care is compromised by bad death or experience
	Facilitates a good death, good enough death, good for the patients or the people left behind, they are the ones remembering

### Theme: Complexities in decision-making

EVE	
	Generally easier with cancer
	Pre-existing problems impact on the palliative phase
	Easier with some cancers e.g. lung cancer rather than ovarian/brain cancer
	Some cancers have a long terminal phase with poor quality of life, others disease can be very rapid
	Unpredictable in timing of dying
	Cancer patients accept diagnosis and usually move on, usually more aware of their situation
	Family influences sometimes conflict with patient choice
FLYNN	
	Cancer different disease with different needs to say neurology, trajectories different
GREG	
	Trajectory is uncertain, palliative care patients have acute events
	Cardiology view is that cancer prognostication is easier – ‘they can teach me’
	Personal reflection – DS 1500 form completed for a patient with 6 months to live alive 4 years later, Libya link Al Megrahi.
	If caring for people with cancer I see them from beginning to end
HERMIONE	
	Prognosis different between different types of cancers e.g. lung versus breast
	Prognosis for certain diseases far worse than cancer, Breast cancer has a good prognosis, compared with HF and COPD
	A lot of patients die of something other than their Breast cancer
	Different perceptions of different cancers <i>re curability</i>
	Easier to give a positive prognosis to cancer patients
	Chemotherapy sometimes delays the inevitable, shock when treatment options exhausted, like being given the diagnosis all over again, grieving process
	For lots of patients <i>poor prognosis</i> may not be a surprise

### Theme: Resourcing

EVE	
	Resources: more hospice beds, more home care, more personnel

FLYNN	
	Need: more beds, more staff, anaesthetic pain control
	Finite resources, under-resourced even for cancer.
	Extension to non-cancer populations would adversely impact on cancer patients e.g. neurology
GREG	
	Originally meant to be cancer and non-cancer
	Non-cancer palliative care more demanding on nurses
	Non cancer palliative care requires different skills
	Would disadvantage cancer patients
HERMIONE	
	Not enough physicians or nurses
	Breast cancer has so many resources in comparison even to other cancers
	Non cancer less access to all support groups or charities e.g. Macmillan

### Theme: Personal experiences and reflections

EVE	
	Father sudden death at home
	Mother cancer death in hospital, uncertain trajectory, gave permission to stop treatment
	Death of one parent different to the death of the second parent
	Treated as a professional when mother was dying ( <i>hospital</i> ), not when father died ( <i>home</i> )
	Mothers burden of caring for father, increasing burden of dependence his death was timely
	<i>'The personal impacting on the professional'</i>
FLYNN	
	Have not influenced the ways I use palliative care services; despite good and bad experiences of close friends and relatives
	Influenced by the personal experience of working with good palliative care doctors who were highly articulate and good educators
	Direct experience of being a palliative care doctor - Gave insight into what it can offer
	Transferable skills linked to my practice as an oncologist especially in relation to managing difficult conversations and

	counselling/psychological support- happy with it myself
GREG	
	Personal experience influenced career my choices as an SHO <i>[reflective example]</i> seeing a surgeon as a bad role model and an oncologist a good role model, decided to be an oncologist 'It would have been palliative care had it existed then'.
	Historical reflections on own experience in palliative care during SpR training.
	When appointed as a new consultant palliative care was not locally accepted, there was pressure on me to support
	Never felt uncomfortable with people who are dying – no problem with it, palliative care has always been part of my life
	Family were non-medical.
	Mother died from heart disease, father from Parkinson's disease both died in old age, their deaths were timely and I was not actively involved.
	<i>'I had already become what I am before they died'</i>
HERMIONE	
	Grandfathers death over 10 years ago when a junior doctor, very present always
	It was a badly managed death at home, largely due to their choices for normality, not wanting sympathy or external help
	My memory retains the worst bits it was ' <i>horrendous</i> ' he was ' <i>opioid toxic and hallucinating</i> '
	Has influenced my own professional role: being open and honest with dying patients, give patients the options, and deal with the root cause of their problems
	<i>'I refer too much, too often'</i>

### Theme: Models of service delivery and provision

EVE	
	Geography and rurality negatively impact on access
	Need to prove outcomes
	Need to prioritise activity
FLYNN	
	Geographical variation in services, difficulties associated with being charity led therefore affluent areas benefit
	Very city centric
	Rurality a problem, rural services less robust
	Patient variables: disadvantaged are those who live alone, have a dysfunctional family, are elderly or very young <i>[reflective examples]</i>



GREG	
	Location of local hospice not ideal related to political and professional influences
	Seamless and integral with oncology services
	Not a separate unit or site
HERMIONE	
	Gaps in services for those who are chronically ill with cancer, managing to live normally – excluded group, no services

### 5.3.3 The old age psychiatrists

The old age psychiatrists were the least similar in their clinical approach to palliative care, the stage in their careers and in gender. The analysis of their interviews mirrored that undertaken for the oncologists. The following list of shared themes was smaller and perhaps influenced by their lack of homogeneity, this was linked to the fact that there were only two of them and so it was difficult to achieve consensus. Their responses therefore are more clearly seen as part of the bigger sample.

- Patterns of Referral (includes past patterns and extrinsic factors impacting on referral practice)
- Perceptions of palliative care
- Complexities of decision-making
- Specialist knowledge
- Personal experience
- Models of service delivery.

The following table provides more detailed descriptive accounts from each of the old age psychiatrists that support and illustrate the superordinate themes emerging from their experiences.

#### OLD AGE PSYCHIATRISTS Ian and Mair.

##### Theme: Patterns of Referral

IAN	
	Yes, 5 years ago used more
	Have experience of things palliative care can and will do <i>'regular pattern'</i> of collaboration and links maintained
	I do what palliative care normally would do
	I refer, but rarely

	Usually use as a telephone resource
	Refer for: medication management, pressure area care, hydration/nutrition, drug therapy.
	Practical skills such as syringe drivers and wound care
	Made for a second opinion, to avoid a complaint.
	Good outcome is no complaints
	Help with specific problems especially agitation and pain
	SPC team respond quickly to referral in comparison with renal services
MAIR	
	For a difficult cancer
	Reciprocity we helped the hospice deal with this lady's mental state and they dealt with her complex physical needs e.g. pain
	Dual diagnosis/multiple pathology
	Resource, they are the 'trouble shooters'
	Personally uncomfortable with cancer diagnosis management.
	Nursing staff recognise deterioration,
	Clues re: impending death
	No real issue or need for referral for end stage dementia
	Don't remember family ever requesting referral

### Theme: Perceptions of palliative care

IAN	
	Professional resource
	Patients not difficult – relatives make it difficult.
	Dementia is a terminal condition at diagnosis
	Terminal diagnosis links with DNAR decisions
	Link nurses educated by palliative care offer supportive psychotherapy or counselling for family members
	Nurses deal with the relatives
	I am the ' <i>drug merchant</i> ', nurses deal with the relationships
	My other role relates to sectioning and medico-legal stuff
	Largely self sufficient in relation to palliative care
	Patient suicide more of a problem

	Role <i>'making sure things are kept tidy'</i>
MAIR	
	Complex issues in dementia relate to capacity,
	Decisions related to withholding withdrawing treatments
	Divergence between mental health and physical nursing
	Palliative care is a satisfying
	Its about knowing a man who does, <i>[specialist resource]</i> but doing the basics yourself
	Not as challenging as <i>'suicide risk assessment'</i>
	There are <i>'worse things than dying'</i>

### Theme: Complexities in decision making

IAN	
	Don't try to make a prognosis, dementia is a terminal condition
	Predisposing factors/co-morbidities that impact likely to precipitate the terminal event include chest infection, haemorrhage, septicaemia and MI
	Families compromised by DNAR questions
MAIR	
	End of life can be quite a long process here
	Dementia is a terminal illness but its not an acute event
	<i>'We get patients that simply die of their dementia'</i>
	You've got to make the decision whether it is palliation or not
	Lady who came for respite [reflective account]
	Pathway validates end of life decision making
	Difficult when people on the pathway and then rally <i>'distressing'</i>
	No control over when someone is going to die
	<i>'Its Gods gift' [living and dying]</i>
	<i>Dementia is a terminal disease, people will ask me for time scales early on ...I tell them the national averages and that everybody's different...</i>

### Theme: Specialist Knowledge

IAN	
	Done lots of self learning and up-skilling

	Other professional activity involves reflection, aware of the importance of knowledge
MAIR	
	Professional updating for CPD, do more medicine in old age psychiatry. <i>[Reflected on a recent course attended with palliative care sessions]</i>

### Theme: Personal experience and reflection

IAN	
	Exposure to personal death - minimal
	Grandmothers death when a teenager, she just <i>'disappeared'</i>
	Reflective professional stories of death
	Current role suicide much more of a serious issue made more problematic because of public perceptions
	Personal dichotomy, have an objectivity about death but <i>'suspect that I'm more vulnerable than I would like to think'</i>
MAIR	
	Strong religious faith influences
	Father died suddenly from a stroke, a good death
	<i>'There are worse things than dying'</i>

The old age psychiatry dyad did not explicitly mention resourcing, models of service delivery or nurses as specific issues. My initial thoughts relate to the historical and pragmatic under-funding of mental health services and that for both participants, palliative and end-of-life care, although important was the least troubling element of their clinical roles.

### 5.3.4 Conclusion

In summary, the initial descriptive approach to analysis for this thesis involved a number of distinct stages.

- Annotation of the transcripts and concurrent listening to the audio recording
- Identification of subject headings, I was not sure if they were themes but each participants responses were tabulated under those headings
- The free text writing on *post-it* notes of the participants' responses using the tables as a template

- The free text then reordered to compare and contrast the descriptive experiences of each of the participants
- Direct quotes inserted into the free text to demonstrate congruence between their words and my description
- After the initial free text draft was written, using minimal direct quotes, each of the interviews was listened to again and the transcript revisited to elicit quotes that supported the themes described
- Audio recordings revisited to check for paralinguistic elements and to enable my immersion back into the story of their experience
- The text was altered subsequent to this in an attempt to pay attention to the 'hermeneutic circle'
- The individual interviews were then revisited to consider the linguistic elements (Chapter 11)

This descriptive analysis aimed to get as close as possible to the quality of their experience by looking through the participants eyes prior to interpretation.

## **5.4 CONCEPTUAL DATA ANALYSIS**

### **5.4.1 Overview**

Jonathan Smith who is credited with developing IPA, characterises its approach to conceptual data analysis as being 'an attempt to unravel the meanings contained in accounts through a purpose of interpretative engagement with the texts and transcripts' (Smith 1997:189). Thus in moving the descriptive analysis from the identification of individual themes to shared themes, group level analysis was undertaken using specific techniques which may establish validity. This approach seeks to elicit patterns and connections between the emergent themes by exploring the interview transcripts of all the participants across all three consultant groups by the process of looking at and exploring the emerging themes and trying to establish connections between them.

The techniques employed were alluded to earlier in this chapter but are described in greater detail here as they support the interpretive approach taken to conceptual analysis. They include abstraction, putting like with like and developing a new name for the theme, subsumption, whereby the emergent themes are accorded superior status by helping to bring together a series of related themes, polarisation, which relates to the identification of

oppositional relationships, differences rather than similarities (negatives and positives), contextualisation, which relates to local and professional intelligence in identification of the contextual and narrative themes, numeration, the frequency with which a theme is mentioned which perhaps suggests its relative importance and relevance to the participant and function, themes that have a specific function in particular what they elicit from the listener.

Smith et al (2009) suggest that these approaches enable a more confident and competent approach to making the most of the data that 'facilitates the development of good enough analysis' (Chapter 5). Most of their case study examples relate to psychology, but their organisational approaches to data management appear easily transferable to the data derived for this health care thesis. The purpose of these techniques is to enable a deeper understanding of the text, immersion with data and hence of the participants' experience which draws on sources associated with narrative analysis.

#### **5.4.2 Conceptual data analysis - the process**

IPA is clearly interested in both phenomenology and interpretation, much published research appears to privilege and be more concerned with the hermeneutic dimension which is the sense making of the participants' experience. Such processes are necessary in order to make sense of the consultants' personal world through a process of interpretative activity. However the consultants' experience is the one irreducible thing, my thesis, when written up, should strike a chord with the reader and give them a sense of what the participants' experience is like and how they experience it and will seek to equally privilege both the phenomenological and interpretative elements of IPA.

The moving from descriptive to conceptual analysis shifts the focus from the particular to a shared meaning and understanding. It is important to acknowledge at the outset that this interpretation is likely to be influenced by my own professional knowledge and experiences. Closer scrutiny and revisiting of the transcripts and the audio recordings supported the

identification of more inclusive conceptual and interpretative themes, superordinate themes. This was achieved by a kind of Gadamerian conversation between:

- My own pre-existing professional and personal understandings in using myself to help make sense of the participants' experience not vice versa (although this was undertaken with caution)
- Understandings influenced by the participants' stories and experiences
- Checking out the meanings for the participants by the use of the hermeneutic circle acknowledging that description always involves interpretation
- Acknowledging there are clear differences for the participant in relation to their understandings in the past, the present and the potential future
- For experience that is beyond our own, being free in opening up of wide-ranging possibilities in understanding
- Achieving a synergy between description and interpretation, that is the gestalt of the individual experience.

This section describes the movement from descriptive analysis towards a more multilayered phenomenological and interpretative (meaning making) analysis.

Smith & Osborn cited in Smith (2008) state that IPA analysis is recognisable and characterised by a set of common processes, those being movement from the particular to the shared experience and from descriptive to interpretative analysis. Together with the common principles of a commitment to understanding the participants point of view by focussing on personal meaning making in relation to the particular context of end of life care. The end point should be the achievement of an account of how the researcher analyses the data and reflects their thinking about how the participant is thinking.

For me, the process involved stripping away my preconceptions or being more consciously aware of them, this will be explored in Chapter 12 which considers quality issues such as openness and reflexivity. I tried to consider 'the flesh and bones' of their experience.

A number of phenomenological ways of thinking about the data analysis were helpful (Polkinghorne 2005; Eatough [Masterclass] 2011). In particular the

notions of 'dwelling' in the data, being immersed and wrapped up in the data which is evident throughout the IPA approach and in vertical depth interpretation which involves tunnelling down, fleshing out the experience, getting your 'hands dirty', focussing on depth rather than breadth as in Eve's experiences of parental bereavement and the identification of 'little gems' whereby a phrase or story jumps out which seems to capture the essence of what is going on with the participant (an example of this was Chris describing himself as 'death denying').

Identifying metaphors and other linguistic elements which provide rich ways of illuminating the analysis, this was consistently present in all the participants' experiences. Its importance is acknowledged in this thesis as it is presented as a separate chapter. Finally the acknowledgement and influence of the part and the whole (the hermeneutic circle), for example, a word in a sentence or an event that illuminates the participants' life world; for them a pivotal experience. This was clearly apparent in Greg's story of how he became an oncologist rather than a surgeon.

Smith et al (2009) suggest that using the stages of the hermeneutic cycle is a useful reference point and a way of thinking that relates to the IPA approach.

The part	The whole
The single word	The sentence in which the word is embedded
The single extract	The complete text
The particular text	The complete "oeuvre"
The interviewer	The research project
The single episode	The complete life.

**Smith, Flowers & Larkin (2009 p.28)**

The hermeneutic circle is both a systematic and a creative approach that involves a dynamic, iterative movement between the part and the whole.

The meaning of the word only becomes clear when seen in the context of the whole sentence. At the same time, the meaning of



the sentence depends on the cumulative meanings of the individual words (Smith et al 2009:28).

There is an element of pushing the analysis, the experience is grounded and developed from the participants' own words but like an elastic band it can be stretched quite far but the stretching needs to stop before it snaps, if it snaps the connection with their experience is lost.

In considering the hermeneutic layers of analysis Eatough (Masterclass 2011) provided a useful analogy in that the interview transcript is a house, analysis involves demolishing the house and sorting the construction materials, the specific sorting of bricks, tiles and timber relates to thematic analysis in identifying the master themes. The next stage involves rebuilding the house; it would be the same house as it uses the same materials but it would also be a different house because it is put together with my interpretations.

It is about retaining and embedding the richness and texture of the individual experience in more abstract general articulation (Eatough [Masterclass] 2011).

Prior to interpretation it felt important to get as close as possible in order to gain understanding of the consultants' experience, this is described as either looking through the participants' eye or lens. The skills required in this process involve description, clarification, elucidation and illumination (Husserl 1970).

The interpretation offered in this thesis will attempt to be credible and accurately interpretive rather than theoretical but as Squire et al (2008) acknowledge, narrative data can easily seem overwhelmingly susceptible to endless interpretation, which by turns is inconsequential and deeply meaningful. Therefore, in order to make the narratives more manageable, when thinking about the transcripts I attempted to consider the 'what if' dimension as a way of imagining and entering into the participants experience/world. It was about thinking, what if this were me; it is not me but what if it was? Whilst this approach is helpful, it requires a delicate balance as I may have attached more importance to elements of their experience than

the consultants would have done themselves. What I identified as valuable, or Greg's 'little gem', may have been throw away lines that the participants may not even remember and that I might attach unwarranted importance to. This is a key tension in interpretative research and will be explored further in Chapter 12 which considers reflexivity and openness.

In an attempt to further enrich and deepen the analysis particular phenomenological concepts and theories have been identified, acting as both a mechanism to explore the experience and make some sense or meaning from the data. The hope being that it may resonate with the experience of others involved in everyday clinical practice in end of life care.

The IPA literature describes these phenomenological concepts as relating to 'hot cognition' being current issues that are emotive and dilemmatic and 'cool cognition' which are longer term issues, reflection across the life course of the individual experience. Using a mind map approach the subordinate themes of patterns of referral, clinical factors at the end of life, complexities in decision making, prognostication, perceptions of palliative care, specialist knowledge and personal experience models of service delivery and resourcing were combined. As a check for consistency the subordinate themes were also combined visually (using the post-it notes). Following this the structural master (superordinate) themes of **referral** and **decision making** were identified. To support more in depth exploration and discussion they were extrapolated into the theoretical themes of **clinical thinking** and **knowledge in (and for) practice**. These fulfil the hot and cool cognitions of the participants' experience.

To ensure appropriate attention is paid to the phenomenological and interpretative elements of IPA and to support its requirements for enriching and deepening analysis, the phenomenological concepts and theories of **being with** (Finlay 2010) and **being in** the dimensions of the **life-world** (Ashworth 2003; Todres 2007) have also been identified in the consultants stories. These will also inform and structure the discussion chapters (9 and 10).

## 5.5 REFLECTIONS

I initially struggled to make the distinction between IPA and traditional interpretive phenomenology and achieve clarity of understanding. I believe that the appropriateness of IPA lies in the role of the researcher, its prescribed intellectual and analytical activity and how it deals with questions of quality.

As previously discussed, one of the advantages in using IPA is related to its structured approach to data analysis and management. Smith et al (2009) have proposed what appears to be a slightly prescriptive framework, their rationale being to support more novice researchers in making the process of data analysis more manageable and less overwhelming. The suggested steps attempt to lessen the risk of being ‘drowned by the data’ and being overwhelmed by the thoughts of managing and making sense of it. For me this approach was facilitative but still supported flexibility in dealing with the transcripts, preserving the individual ‘voice’ of my participants as part of the shared or common experience. It also supported a more interpretative and eclectic theoretical approach to achieving understanding of the consultants’ experience.

## 5.6 CONCLUSION

This chapter has presented a description of the participants’ experience. It outlined the activities and approaches associated with descriptive and conceptual data analysis in IPA that linked together the analytical method and findings.

The analysis identified subordinate themes that were related to the structural contexts of care and were combined to form the master themes of *referral* and *decision making*. These encompass past patterns of referral, internal and external factors impacting on referral practice and decision making. Chapters 6 to 8 will present descriptive accounts of the consultants’ individual and shared experiences, locating the discussion within contemporary health and palliative care practice and considering patient and professional perspectives of palliative care – the structural context.

The theoretical contexts emerging as influencing the consultants experience and practice are *the life-world*, *clinical thinking* and *knowledge in (and for) practice*, they provide more phenomenological and interpretative perspectives in which to deepen the exploration. These dimensions of the consultants' experience together with linguistic analysis will be presented later in Chapters 9 to 11 of the thesis.

## CHAPTER 6 - THE CARDIOLOGISTS

**In cardiology we can make people better and that's great and that's why I like doing it but you have to accept that there are times when you can't make somebody better. (Dan).**

### 6.1 INTRODUCTION

This chapter will provide a descriptive account of the experience of the consultant cardiologists, it will initially present short biographical details of each of the cardiologists before describing their unique experiences. The second part of the chapter will describe the patterns and connections between them as a group in an attempt to present their shared experiences.

The cardiologists were the first group of participants accessed for this thesis. One individual with whom I had worked, together with the identified gatekeeper (see Chapter 4), in developing strategy documents, was very committed and supportive of the thesis, and participated enthusiastically. This enthusiasm was infectious as his colleagues readily became involved, perhaps demonstrating the positive effect of snowballing and the idea 'that it is not what you know it is who you know and who knows you' (Blackburn 2011 personal communication).

All the cardiologists within the geographical area identified were men, as are the great majority of the cardiologists in Wales, reflecting the UK wide profile of the speciality where females make up 60% of medical-school applicants but only 17% of cardiology trainees, and just over 7% of cardiac consultants. All the participants in the study were men reflecting the gender dominance of cardiologists in the UK (British Cardiovascular Society working group 2006). The geographical area in which they practice is mixed with metropolitan, urban and rural populations. It is an area of socio-economic deprivation with high levels of cardiac disease.

## 6.2 THEIR IDIOGRAPHIC EXPERIENCE

### 6.2.1 Alex

Alex is in his late fifties, he describes himself as a 'therapeutic cardiologist' and is very much involved in political and strategic initiatives at both local and national levels. It felt as though he was very patient centric as before and after the interview he talked mainly about patients and the difficulties they experience carrying the 'burden' of heart failure. This was less apparent during the interview. He was very warm and supportive, clearly motivating his colleagues to be part of this study. His family are very important to him, he has experience of close family members being compromised by chronic illness but no-one close to him has died. He is planning to retire early in order to do voluntary work in the developing world.

Alex's interview was characterised by a thoughtful, measured approach, this was particularly evident when he reflected on clinical incidents. He spoke in a constant tone, occasionally some points were given more emphasis especially those related to resource inequity and the importance of nurses. He was less hesitant and his voice and speech more free flowing when he was in his 'comfort zone'; which was when he was talking about the more physiological and technical aspects of cardiac care.

It appeared that for Alex there was a clear distinction between active and palliative treatments, characterised by polarity between optimism and pessimism: light and dark. His theoretical understanding of palliative care was evident but there was some difficulty in linking this to his cardiology practice.

For him it was the issues related to clinical judgement and decision making contingent on palliative care referral that were tricky, characterised by uncertainty and hesitancy. This was demonstrated by what he said and how it was said. For example in relation to decision-making this long extract *[which is presented verbatim complete with paralanguage, pauses and hesitancies]* exemplifies his ambivalence, almost reluctance, to consider referral:

I think that decision is...is quite a delicate one really as to when exactly do you refer, um...its often difficult with

heart failure to define an end point...um, you know, um...it emphasises that difficulty of knowing when the patient is going to succumb from their condition and the timing prior to that to introduce palliative care services so I think we...we...we find that um actually um you know putting...giving the patient that...that knowledge that it could lead to terminal decline is a...is a very difficult decision and a lot of patients with heart failure do very well for a long period of time on...on um drug therapy and so on so...introducing a sort of rather depressive um outcome to their management may have deleterious effects anyway on their psychology and so on so...psychological response to their illness so I'd prefer not to introduce that unless its...its fairly near the time (Alex).

The extract from his interview appears to suggest both the clinical responsibility in identifying end of life and also an element of culpability in that it may precipitate a terminal decline either physical or psychological. This links with the belief in a self-fulfilling prophecy, that 'voodoo kills' that once something is said it will come to pass and by articulating that someone is close to death it makes that death imminent and certain. The professional responsibility imbues the physician with an almost God-like status in having power over life and death. This was acknowledged in some of the other participant interviews but it was only Alex who so clearly linked the 'cause and effect', a potentially harmful consequence of referral to palliative care. The idea of 'voodoo kills' will be discussed in greater depth in the later discussion chapter.

Thus Alex was clear that his perceived clinical power and responsibility should be exercised with caution and probity. In the more personal elements of the interview he explicated the practical dilemma of needing to refer but that it was complex:

We shouldn't really prevent ourselves from sending the patient on but I think we probably need to discuss guidelines. I think there is a risk that perhaps um having referred a patient for palliative care, that you may feel that there is nothing further you can do anyway and then there's a sort of almost a sort of pulling back maybe not an active pulling back but perhaps a passive pulling back of involvement and therapies and so on and a belief that

you know the patient is at the end of the road and someone else is taking care of them so there is that aspect as well (Alex).

The visual image that emerged from this extract was of a tug of war, with cardiology and palliative care being at either ends of the rope and the patient being in the middle, being pulled one way and then the other. Eventually the cardiac team were overwhelmed and lost the encounter with the patient becoming part of the palliative care team. Implicitly there feels a sense of loss and perhaps failure which is supported by Alex's earlier comment: that for him referral is like admitting defeat.

My interview with Alex was the first conducted for this thesis and my inexperience is reflected by the fact that I did not pursue this idea of bereavement and disappointment but focussed on the relationship with the patient and transitions. Perhaps this was consistent with my awareness that this was a difficult issue for Alex and that I was conscious of perhaps opening up 'a can of worms'. For much of the interview he did stay close to the idea of palliative care having negative connotations which was at odds with his strategic profile which he described as facilitating and incorporating palliative care into cardiology practice. Interestingly, supporting his distancing from palliative care, he sees this shared care approach being managed at the nursing level.

### **6.2.2 Ben**

Ben, in his late twenties, is the youngest of the cardiologists and a newly appointed consultant. He has by his own admission more limited life experiences and no personal experience of death and dying, he is clear that this is related to his comparative 'youth'. Ben was more pragmatic and prescriptive in his approach being very involved in technical interventions, in particular the idea of a plastic heart being able to maintain and keep people with heart failure stable whilst waiting for a transplant. BBC News reported the first patient experience of this just a year after my interview with Ben (BBC News 2/8/2011). He describes himself as an 'interventional cardiologist', being constantly compromised in practice, especially because of finite



resources. He was more guarded in the personal information he disclosed but has aspirations of a more strategic role in the future when he is less of a neophyte consultant.

Ben's interview was characterised by a fast pace, the rhythm of questions and answers felt almost like verbal sparring, the answers were precise with no real reflective or individual patient elements influencing his responses. It felt like a very polite, professional and almost distant encounter in that I was kept at 'arms length'. There was very little hesitation or uncertainty in his responses. I was aware that throughout the interview he was almost apologetic about his lack of personal experience. Most of his replies resembled those of his colleagues, his individual viewpoint was influenced by and almost exclusively related to his professional role as a tertiary specialist, where after providing active treatments his patients are sent back to their original team for ongoing care.

Specific concerns were related to his individual excessive workload and his wider political concerns of resource inadequacies and inequities across all aspects of cardiology services:

the development of heart failure services has been appalling compared to most parts of England ... so up until very recently there's been no funding for heart failure services in [*named geographical area*] (Ben).

The consequences being that even the basic services are compromised by inadequate facilities so holistic care is not even an option.

Ben has taken local action to resolve some of these concerns in practice, in his new job plan which is currently being negotiated he is hoping for 'two sessions every six weeks dedicated to heart failure, so that's where we are'. I reflected that this seemed a very small amount of time but he was clear that pragmatically this was all he was likely to achieve in the current resource compromised NHS. As an adjunct he was preparing bids and lobbying the voluntary sector to establish a heart failure nurse specialist post 'a liaison

person' as filling the gap between the aggressive cardiological approach and the palliative approach. Like Alex he sees this as primarily a nursing role.

Reflecting on what he perceives as the gold standard he describes the pulmonary hypertension service in London:

they might have heart follow up conversation/consultation with the doctor and then spend an hour, hour and half with the pulmonary hypertension nurse afterwards to have any questions or queries answered and plans for non-medical management considered and how they are coping at home and social aspects of care and things like that (Ben).

This service was holistic and not time or resource constrained.

### **6.2.3 Chris**

Chris is in his mid forties and a Clinical Director, describing himself as a 'Jack of all Trades cardiologist who appeared, and felt he had to be, organised. He is very active and a marathon runner. He was very measured in his responses, sought clarification of the questions – but appeared very positive about palliative care. He described many personal experiences, specifically his mother died from a brain tumour when he had just qualified as a doctor. He believes this event has impacted on how he views death stating that although 'it is inevitable, it needs management'. His wife is a nurse and they are currently caring for his father who is very ill. Subsequent to participating in the interview Chris' father died.

The unique element of Chris' experience is the extent to which his personal experiences of palliative care have influenced his clinical practice, and how he sees the nature of palliative care in cancer being transferable to the heart failure patient population. These experiences have shaped his views of death and dying; he describes a very fatalistic approach to death and a very pragmatic view of the process of dying.

Chris is the only participant who talks about death as being manageable, providing evidence that supports this stance as being apposite in practice. He

describes the use of interventions that may hasten death, in his mothers' case this was the use of a subcutaneous syringe driver.

In relation to heart failure where the withdrawal of interventions may precipitate death he describes:

they may, for example, be on inotropic support in hospital and you know that withdrawing that support will end up in their earlier demise (Chris).

On reflection, Chris appeared to consider these interventions as appropriate but that it appears 'very medicalised' and is about making 'value judgements'. The aspects of initiating, withholding and withdrawing of interventions are based on the intent underpinning the decision and the ethical dimension of practice. His approach appears to be informed by his mothers' death:

it was quite clear what the outcome was going to be and prolonging the agony was just not appropriate but I'm that's a very medicalised view of the world and um these are value judgements we put on things I think yes (Chris).

During his interview Chris was comfortable with the personal elements of his life impacting on his professional practice. This influence was unique in that it appeared to make him believe that death can be managed to some extent, this was evident by his clarity related to the ending of active interventions, less clear was his understanding of palliative care being an active speciality. Although aware of the inevitability of death he was resolutely death denying, wanting to personally die as late as possible.

#### **6.2.4 Dan**

Dan is in his early forties and describes himself as a 'jobbing cardiologist', he feels very positive about palliative care and the importance of its shared approach. He feels that specific issues related to heart failure are not always captured by conventional palliative care. Personal experiences have shaped him in that he is now more comfortable in facing death, in talking and thinking about it. He talked very freely about his wife's sister who had recently died, very young and unexpectedly in childbirth. He is a cyclist and is involved in

long distance expeditions to raise money for charity. Dan works in a different geographical location to the other cardiologists and heart failure nurses are an integral part of his inter-professional team.

Dan's unique perspective is characterised by close links with the local palliative care team and the heart failure CNS being a resource to his team. He is able to articulate, from direct experience, what the nursing role offers and how it impacts on his practice. The clinical dilemma being that heart failure nurses have an input at all stages of the patients journey, end of life care being in direct competition for resources with patients who are newly diagnosed:

The resources aren't there. The resources we have are our heart failure nurses, but they are being used in other ways. So if you start saying to them we've got two or three patients, all it needs is two patients who are end of life at home...then their time commitment would be daily going out to see them but as a result of that they couldn't run the service we want them to run which is seeing new patients, counsel the families, titrate up established patients they just can't do it (Dan).

His integrative approach to palliative care is evidenced in that he is the only cardiologist who discusses the last days of life pathway as a means to facilitating advance care planning and proactive decision making. It is a way of making explicit that aims of care have shifted from cure to comfort. The difficulties associated with the pathway relate to the uncertain disease trajectory of heart failure whereby patients go on and off it but this for him pragmatically is just how it is in practice. The benefits outweigh the detriments; it is an approach that helps to achieve 'the best outcome best mode of death or the best managed death'.

Dan's interview is characterised by a more assured way of responding and speaking, he describes a certainty in relation to his own clinical role and in dealing with uncertainty that it is possible to be certain in dealing with uncertainty. He appears to be at times quite prescriptive as to how other team members should behave, describing himself as the 'team leader and strategic visionary'.

### **6.2.5 Conclusion**

The cardiologists were the most similar as a group. One of the problems of accessing such a homogenous sample of participants is that the commonality of their shared experience has in part silenced or at best muted the individual voice. It has been difficult to extrapolate what was unique and the preceding section feels a little contrived. It is a required element of IPA analysis and has thus been attempted but it is possible that in some instances their professional role has subsumed the individual and so is less present.

## **6.3 THE CARDIOLOGISTS SHARED EXPERIENCE**

### **6.3.1 Introduction**

The comments from each of the other three cardiologists were grouped together and linked with the themes derived from Alex's interview. Any unique or previously unidentified themes were also stuck to the flip charts for later attention. Linguistic interpretation was undertaken by considering the specific use of language; metaphor was the element of language focussed on, paralinguistic comments were annotated on the interview transcripts and are presented separately in Chapter 11.

As outlined previously, the subordinate themes derived from this approach and which reflect the experiences of all the cardiologists were:

- Patterns of referral
- Perceptions of palliative care
- Complexities of decision-making
- Resourcing
- Specialist knowledge
- Personal experience
- Models of service delivery
- Nurses

### **6.3.2 The shared experience**

The stories of their experiences appeared to be influenced by their perceptions of palliative care, its perceived historical and current place in health care, issues related to clinical judgement and knowledge and individual patient and family factors. Their answers demonstrated a reflective

questioning of their practice but also some ambivalence towards palliative care.

Their own specialist knowledge related to heart failure enabled them to manage most patients; they were especially familiar with the patterns of decline and recovery associated with the heart failure trajectory. Chris explained that most patients are not referred to palliative care because 'as cardiologists we would be able to deal with their exacerbations and hopefully get them on to a more stable trajectory enabling patients to return home'.

As a group they reflected on the complexity and uniqueness of their clinical speciality as providing justification for their reluctance to refer; their distinct clinical knowledge being crucial to the care of their patients'. This clinical knowledge was validated by examples, given in each of their interviews, of their technical expertise and physiological awareness which was not held by palliative care specialists. As described by Ben, palliative care specialists apparently have a small skill set relying on the use of three types of medication: analgesics, anti-anxiolytics and sedatives, which are bespoke and related to those predominantly with cancer. Reluctance to refer is linked to the perceived lack of experience and expertise of palliative care doctors in the management of heart failure.

As a group sharing a common speciality they were unique in that they referred internally between themselves, almost having specific skills and responsibilities that contributed to the breadth of their service. They were more theoretical in their understanding of palliative care and its relevance for heart failure. They tended to refer individuals with co-morbidities rather than for heart failure itself. Their responses to my first open interview question, 'I wonder if you could tell me if you have ever referred any of your heart failure patients to palliative care', were similar. Alex stated that he had not actually referred directly for heart failure and reflected on a patient that he had referred to palliative care many years ago because he had other intractable problems, in particular pain. Although it was a number of years ago Alex remembered because referral was an unusual situation that was not part of his routine care.

Ben concurred and explained that he refers infrequently because traditionally the palliative care services in this geographical location were only funded to see patients with cancer, patients with heart failure were refused access. Ben, unique among the participants, provides a tertiary service and refers people back to their local services when their heart failure is no longer responsive to active interventions so he rarely encounters end of life issues except following an acute unexpected event. He reluctantly acknowledged that alternative perspectives on care may have some value; 'it is sometimes useful to see things from a different perspective and have their input'.

Chris refers only when no conventional options are left, also referring very infrequently and at the very end of life. Reflecting on one particular experience when it was likely that his patient was going to die with end stage heart failure and it was established there was no further intervention that was going to reverse or stabilise their condition he describes referral as being helpful, with the aim of keeping the person as comfortable as possible until their death.

Dan refers for a minority of his patients, mainly because he perceives palliative care as a 'cancer-centric' service. He describes an ideal service that would enable his patients to use the resources and expertise that palliative care could offer. Dan gave a reflective example of a patient who received palliative care from the local hospice team enabling him to receive the required intravenous medication and die at home as being an appropriate referral, this patient was cared for about six or seven years ago. He believes that his team would now have the skills and resources to care for that individual themselves. Currently, for most patients, the cardiology team have the necessary skills so referral is rarely indicated.

Referral therefore, if made at all, was made at the very end, the last resort perhaps. Alex reflects that perhaps as a group they should refer more. Chris suggests that referral would only be appropriate for a highly selected group of patients, largely because of the historical limited availability of services. He uses palliative care services more as a resource, as a consultation service;

stating 'only in extreme circumstances' would they be the prime carers. The length of the heart failure trajectory and the consequent relationship between the cardiologists and their patients seemed also to militate against referral in that there was a feeling of a shared journey together.

The nomenclature of heart failure impacts on physicians, their management and decision making. Alex believes that the condition:

Has a bad name, the terminology is poor because patients when told they have heart failure almost immediately think their heart is going to stop or give up working, and I think an alternative term would be very much better and often I think professionals do tend to avoid the term [*heart failure*] in order not to give it that sort of pessimistic air you know to treat them with a degree of optimism for a period which a lot of patients benefit from I think (Alex).

Despite much debate between us it was not possible for Alex to identify a more user-friendly less value laden name. The choice of words in that extract, optimistic and pessimistic, seemed to characterise the cardiologists approach to their patients as being very hopeful, that their interventions and management were pursued with a positive intent. It also raises the issue of binary opposites that will be explored more fully in Chapter 11.

The cardiologists describe the mixed meanings that the diagnosis holds for their patients; for some it appears to evoke fears of sudden unpredictable death as a consequence of their heart failing. For others it suggests a gradual decrease in activity and function and for a smaller group they expect very active, invasive interventions such as a heart transplant or pacemaker insertion. These differences in patient perceptions appear to impact on clinical management, whether it is active or passive. Ben suggests these perceptions are reinforced by the media and public understanding of heart failure as being

somebody drops down dead you know, suddenly within the course of a few minutes or a few hours; they don't see it as a sort of chronic debilitating condition which it is for most people (Ben).



For Ben's patients mention of 'palliative care was often a message of surprise'. Chris contradicts this perception believing that his patients have a good awareness but are more comfortable in thinking of it as a chronic rather than a terminal disease.

All the cardiologists recognised that in their information giving related to a diagnosis of heart failure they always highlighted a reduced life expectancy; it was a surprise that despite this information patients perceived that they were not terminal or suffering from a life threatening condition. Most patients and families focussed on active treatment and management that appeared to influence and in turn be influenced by the interventionist approach of the cardiologists. Alex suggested that patients' lack of awareness of the severity of their condition and the focus on the positive is possibly as much a fault of the professionals looking after them as anything else, partly because of cardiologists' lack of comfort with talking about death and dying. Although it is clear from the interviews that many of their therapeutic approaches and interventions have an implicit palliative intent and are focussed on maintaining comfort.

Dan believes that for his patients, counselling at the beginning sets the scene by being clear that they have a serious diagnosis that carries with it a significantly reduced life expectancy. He was the only cardiologist to have a specialist nurse in his team and was clearly able to identify the nurses' supportive role in information giving, especially in being able to broach the subject of chances of dying and discuss advanced care planning issues before they become too ill to make any decisions. For Dan it was obvious that heart failure nurses have more skills in relation to end of life care and he acknowledged their role in facilitating what he describes 'as a good death for these people'.

The unpredictable HF disease trajectory makes identification of the 'tipping point', of recognising imminent dying, as problematic. It was troubling for the clinicians but all reflected that this is also the case for patients and families who have lived with uncertainty often for many years, this uncertainty being

characterised by many false alarms and 'Lazarus' like experiences. Ben describes that, unlike cancer, heart failure is characterised by prognostic uncertainty:

With heart failure it's all very, very much more difficult, you see patients who you think are dying and then two years later they are still coming to the clinic so its very difficult to make that decision and say 'right from now you're a palliative care patient' (Ben).

Cardiology explicitly focuses on active treatment, further reinforcing the distinction between active and passive approaches to care. Chris describes cardiology as having 'lots of therapeutic options'. All the participants made reference to always being able to offer something from their clinical skill set that would ameliorate patients physical distress, it was unclear whether their interventions were active, palliative or placebo in intent as they appeared linked with their need to maintain an optimistic approach and being a response to patient and family expectations. Alex describes the outpatient interaction as being when patients and families come up to the clinic, they expect some changes and there is always something you can do, fine tuning of the treatment and so on.

The difference between cardiology and palliative care is quite specifically described by Ben reflecting that the palliative care physicians tend to go down the track of analgesics, sedatives, anxiolytics, whereas they see people who are breathless and look at it from a cardiovascular perspective to try and get rid of fluid and vasodilate them and deal with issues that are causing the breathlessness rather than dealing with the symptoms.

Cardiology appears to be imbued with a more expert technological approach. Dan articulates this and describes the complexities and dilemmas associated with heart failure management highlighting that there are a number of different possible scenarios linked to disease progression:

Once it gets beyond a certain point they're at high risk of death from arrhythmia which is in terms of mode of death that's very quick but you also have the problem where they go into worsening heart failure with fluid retention, pulmonary oedema, renal failure and quite

often it's the renal failure heart failure balance that does it. Any concomitant illness like diarrhoeal illness at the end when they've no reserves so they tip right over into renal failure and its not a nice way to die but its hard to predict the actual, the death of anyone I think with heart failure they can be stable it just needs one little extra insult that tips them over the top very quickly (Dan).

In response I asked:

And perhaps may the opposite be true as well in that they can look as if they are coming to the end (Sally)

Dan continues:

...then they bounce back and that's certainly happened. We've certainly had patients in the hospital, withdrawn all treatment because they are dying, end of life pathway you know, final days and then they perk up a treat when you withdraw the treatments usually due to fluid and balance and fluid in the right place and suddenly everything's better and they go home again. So its one of the difficulties of the final days pathway but people go on and off it and as long as we accept that if we treated them in hospital, we put them on this pathway they can get better, they rally and they come of it again and go home sometimes. It is a difficult situation for everybody, doctors, nurses', family particularly (Dan).

This dialogue perhaps demonstrates a shared understanding between Dan and I in relation to the clinical difficulties intrinsic to the care of an individual with heart failure. Specifically, in debating the end of life pathway as a framework for care to work with. It is evidence based and in the public domain, easy to use, flexible and not fixed, so that people who rally can come off the pathway. For Dan it supports the team approach with 'the patient at the centre' delivering what is needed and facilitating complex decision making.

The family's need for support, or their active seeking of help, encourage referral, Alex, Ben and Dan all acknowledged that the family acted as motivators for or against referral. Referral they suggest is relevant for articulate, communicating and coping families, this is contradictory to the oncologists' experience who referred patients to palliative care when their families were *not* coping and communicating. Chris struggled with thinking about, and understanding, the part played by families in encouraging palliative

care involvement in that it was not part of his clinical experience. Later he described this approach to care as relating to his belief that there are lots of therapeutic options available to him as a cardiologist but when there is a clear downhill trend, as part of the natural progression of the disease, then he believes it is up to him to initiate discussions. In questioning him as to how he explored the imminence of death with families I asked him to reflect on his approach. He described it as an evolutionary process rather than a sudden revelation, being part of a care continuum that resonates with the disease journey.

The imparting of knowledge to the patient related to a terminal decline and the consequent timing of referral to palliative care are perceived by Alex as having a potentially adverse impact on the patients:

It is a very difficult decision and a lot of patients with heart failure do very well for a long period of time on drug therapy and so on, so introducing a sort of rather depressive outcome to their management may have deleterious effects anyway on their psychology and also on to *their* psychological response to their illness so I'd prefer not to introduce that unless its fairly near that time (Alex).

Chris believes society recognises palliative care as being linked with cancer and death, associated with hospice and that it is somewhere where you go to die. End stage heart failure is not seen as something that requires palliative care.

Personal perspectives, experience and knowing influenced referral for Chris who identified the yardstick for him as the 'grandmother test' or the 'father test'; or what would you want to happen if it was your own relative as influencing his decisions. He then continued to describe the experience of his mother dying of a brain tumour when he was a medical student. This personal experience he acknowledged, often led to him making value judgements about the appropriateness or not of palliative care. On reflection it appeared to me that the linking his own experiences to practice was not an entirely comfortable approach for him, it felt as though the describing of it as

the 'grandmother or father test' rather than the 'mother test' reinforced a personal professional distinction and detachment. His mother's death was clearly influential but still needed to be held back.

Chris indicated that he felt palliative care accelerated his mothers' death. In asking the reflective question 'Do I have any problem with that?' he answered:

At the time it was appropriate and you know it was quite clear what the outcome was going to be and prolonging the agony was just not appropriate but I'm [*struggles a bit, hesitates*] that's a very medicalised view of the world (Chris).

His personal experience of advanced cancer is very different from the situation of heart failure management but for Chris it appeared to suggest that it is often possible to manage the process of dying.

Ben was almost apologetic about his lack of personal or family experience of death and dying, being in the enviable position of having a very fit family. He sees his clinical approach as very much a professional work based thing that he does and enjoys doing, his patients dying is not a regular occurrence. His clinical training included a substantial palliative care rotation which, on reflection, was helpful in helping him come to terms with death and dying. As a consequence he feels comfortable in dealing with people at the end of life and facilitating open discussions. There is some dissonance in relation to what he says and what he does in that he continues by stating that:

I would not generally initiate the discussion about end of life care with a heart failure patient because I like to allow them to make that decision (Ben).

Personal issues related to fears of death, and in particular mode of death, were articulated by Chris and Dan who both believed that this resonates with the fears experienced by their patients and families. Dan was the only cardiologist who discussed the concept of a 'good death'. He had attempted to elicit understanding of its meaning from a professional perspective and from the experiences of his patients and their families. He acknowledges that this understanding was largely influenced from an early and humane exposure to

oncology patients during his training, remembering an inspirational consultant who said:

‘Go and speak to that patient [*and he did remember the mans name*] and ask him what it feels like to be dying’. That was my job so it was a bit of a rough introduction to it but the whole point of it was to say that we’re here to treat patients and not do the impossible and treating patients is sometimes to accept deaths natural outcome; but how do you make it a good death and not a bad death (Dan).

Reflecting on this critical incident demonstrated an acknowledgement, death being a normal and natural part of life. This experience was in opposition to most other elements of his training where the focus and norm for the non-cancer specialities was to ‘look on the bright side say and make people better’.

A good death appears linked to the mode of death, Dan stated that for people with heart failure sudden death is positive, with prolonged dying being negative but it is even more of a disaster if somebody dies in the Emergency Department. For him it is about the ‘best-managed death’ which requires an attitudinal shift on the part of the medical team in changing the goals from cure to care which relies on good communication and experience. Most of the cardiologists recognise the usefulness of the last days of life pathway especially in relation to decision making and articulating more explicitly to patients’ relatives that end of life is imminent.

Dan reflects that the pathway is especially appropriate in dealing with his frail, elderly patient population who manifest many co-morbidities, it ensures that that the goals of care are shared and explicit:

We all know what we’re trying to achieve and there’s a certain sort of satisfaction then about you know seeing somebody who was perhaps distressed no longer distressed and everybody’s comforted by it (Dan).

In relation to his clinical role Alex describes particular difficulties in admitting defeat and handing over his patients care to palliative care. Ben supports this

dilemma, that there are difficulties from his perspective when deciding when a patient becomes palliative:

It's very easy to pass that anxiety over to the patient so you go from the situation where you've got a clear cut goal of getting the patient better, most patients like to have a clear cut goal of what they're trying to achieve and most patients want to carry on want to carry on living for as long as possible and actually very few will raise the issue of, you know, 'where are we going with this doctor' (Ben).

For him it is not the patient but more often the relatives who prompt changes in care goals. This is supported by the old age psychiatrists experience but again is conflicting with the oncologists' experience where it is usually the patients who recognise the need to change the focus of care from cure to palliation.

Dan's perspective on the role of the cardiologist is more pragmatic:

In cardiology we can make people better and that's great and that's why I like doing it but you have to accept that there are times when you can't make somebody better (Dan).

For him it encapsulates the dichotomy in his role between the acute interventionist approach and the approach required at end of life which supports a more passive role for the cardiologist.

For Alex the referral links between palliative care and heart failure services are best facilitated at the CNS level. He believes for nurses there is some overlap of competencies and potential merging of roles involving both specialities working together. This is evident from his strategic role working with the cardiac network, he has no direct clinical experience of this as in his geographical area there are no heart failure nurse specialists.

Inadequate resources impact on service delivery; all acknowledge that traditionally heart failure services in Wales are extremely poorly funded compared to most parts of England. Chris, as clinical director, reflects on local provision:

The gap between where we are now and where we ought to be is quite considerable (Chris).

This is apparent in all aspects of cardiac care, specifically heart failure patients who are a small population with a very big gap in service provision. Resources are very limited, but Chris suggests that cardiac services do not necessarily require new resources but rather reallocation of resources at strategic level and at the operational level of care, more coordination and collaboration. For people with heart failure it is at the diagnosis and actual treatment that the biggest gain is to be had and should get the 'lion's share' of funding. At strategic level it is the Palliative Care Implementation Group (WG 2009) who are exploring resourcing non-cancer palliative care.

For Chris a personal, pragmatic and accepting perspective was the dominant element of his experience:

As with any condition ultimately a heart or cancer will catch up with you mostly or whether its old age and so on (Chris).

These conditions all require seamless access to services at different stages in their journey and heart failure is not unique. He reflected on his current experience in co-ordinating care for his elderly father, being on the other side of the fence, and realising that it is the frail and elderly who are a huge problem. Their care is impacted on by limited access to care compounded by poor organisation and communication between primary and secondary care.

The myriad of roles intrinsic in the medical consultants' role impacts on their clinical activity and requires constant juggling. Ben describes the imperative to manage his personal workload and the difficulties in providing an under resourced and time-constrained service which impacts on his ability to deliver holistic care and his consequent dissatisfaction with that care. From Ben's perspective 20 minute consultations every three to six months militate against eliciting the patients' concerns and feelings about their situation, it focuses predominantly on the medical management:

We don't really have the time to go into the detail of, *you know*, the patients feelings about their treatment or where they see things going. Its very much a how are



you, how are you doing, *you know*, what's your weight doing, lets see your kidney tests, what tablets are you taking, do this, do that, have these tests done, *you know*, every month for the next six months and we'll see you in six months if there's no problem (Ben).

In this quote his repeated use of the phrase '*you know*' suggests his acknowledgement that I too am aware of the difficulties associated with clinical care, a shared understanding that links with the stance proposed by IPA.

In thinking about new models of service delivery Alex identified the heart failure nurse as the bridge between cardiology and palliative care, being the conscience of the cardiologist because:

We do sometimes get a little tunnel visioned into as I say medical and device therapy and not thinking perhaps more holistically (Alex).

Heart failure nurses would have more time to deal with patients' holistic concerns. Ben suggests they would fill the gap between the aggressive cardiological approach and the palliative approach. He gave a best practice exemplar of a more patient-centred pulmonary hypertension service model in London that provides an approach whereby the consultant consultation is followed by an information giving and supportive discussion with the CNS the aim being for the patient and family to:

Have any questions or queries answered and plans for non-medical management considered and how they are coping at home and social aspects of their care and things like that (Ben).

Alex describes a preference for a shared model of care where the palliative care team are enabled to come in and out of the patient's care, responding to specific needs such as a symptom control, psychological distress and then withdrawing. This shared care approach would upskill both specialities and could be facilitated by clinical guidance and pathways. Dan supports this approach, as the preference for him would be to carry on his patients care to the end of their life with cardiology as the key clinical team. What would be

helpful to facilitate this would be access to palliative care as a consultancy and resource service.

Dan is already working with a dedicated multi-professional heart failure team, he describes a regional model of care, having someone with expertise and background in heart failure but also in palliative care being available to his team and the wider regional team. He states it would be resource effective and facilitate workload management as there are only a small number of people dying at any one time. This post would be about managing transitions and providing expertise at the end of life. He identifies that ideally it would be a nursing post, having current positive experience of a heart failure nurse being part of his existing multidisciplinary team.

### **6.3.3 Conclusion**

Positive or negative perceptions of palliative care appear to impact on the motivation to refer or not refer, these are derived from both personal and professional experience. Their confidence in their own specialist knowledge related to heart failure enabled them to manage most patients. They were especially familiar with the unpredictable disease trajectory and the difficulties associated with diagnosing dying.

In the cardiologists' interviews there was an element of them trying to balance the technological aspects of their practice with a more personal and humanising approach to their patients. This was more challenging during the transition of care from curative to palliative, from an active to passive role. They predominantly described their skill set as being related to pharmacological and interventionist approaches to care that were linked to the physiological disease processes. They valued these skills as it appeared to make their clinical role very distinct from that of palliative care.

Despite many of their described experiences being very interventionist, there was evidence of them being able to communicate uncertainty to their patients. They appeared able to work with their patients (and families) in a way that

supported a care approach of 'living their dying and death'. That death was acknowledged as a possibility but was not the focus of care.

## **CHAPTER 7 - THE ONCOLOGISTS**

**Palliative care could not exist without oncologists.  
(Greg).**

### **7.1 INTRODUCTION**

This chapter will provide a descriptive account of the experience of the consultant oncologists, it will initially present short biographical details of each of the oncologists before describing their unique experiences. The second part of the chapter will describe the patterns and connections between them as a group in an attempt to present their shared experiences.

The oncologists were a mixed group of two men and two women, working from a Regional Oncology Centre and covering a wide geographical area, with metropolitan, urban and rural localities. It is an area of socio-economic deprivation and high levels of cancer incidence.

### **7.2 THEIR IDIOGRAPHIC EXPERIENCE**

#### **7.2.1 Eve**

Eve is in her early sixties, and is one of two participants previously known to me from when I worked in clinical practice. She stated that she was ready to retire and felt rather cynical about the state of the health service. In preparation for retirement she was about to start working a three day week. Eve shared with me her feelings that she had never quite fitted in to the 'Consultant role' and felt the title made her distant from her patients' direct experiences. She lives and works in a more rural part of the area. Initially Eve appeared quite guarded and nervous but became more talkative and warmer when we discussed her personal experiences. Eve plans to spend her retirement travelling and becoming a smallholder, in talking about a colleague who had a stroke just before he retired, having left it too late, she hopes her timing is better.

The beginning of the interview with Eve was characterised by some hesitancy and nervous laughter, at the time of transcription I reflected that maybe it was a sign of nervousness, after a few minutes it settled and became a more

comfortable interaction. The unique elements of her interview relate to her personal experiences of loss, the geographical location of her clinical practice being more distant from the cancer centre, working among more rural and Welsh-speaking populations, together with her length of time in post which has facilitated familiarity with the local palliative care services.

In relation to personal experience of death she describes the contrasting deaths of her father and mother. Her father died suddenly following an acute event at home, although he had been gradually declining in health over a number of years, whilst her mother died in hospital from advanced cancer, following a substantial period of decline. Her father's dying, though a shock was timely and was a good experience, he died from what was thought to be a dissecting aneurysm. Eve is comforted by her belief that he was unlikely to have been aware of what was happening. The GP who visited, she describes as 'doing the right thing' in that she certified her father as dead and, despite probably not wanting to, stayed for a cup of tea and just listened. Eve reflects that the family were more in control being at home, that it was a relief that he had not survived to be 'barely alive, being looked after', her mother having the burden of caring.

The experience of both these deaths, she perceived, was influenced by her professional status in that there was an expectation by others that she would want involvement in clinical decisions. In the case of her father this was related to the necessity, or not, of a post mortem to establish the cause of death, she describes postulating a theory as to the cause of his death and this being accepted by the primary care team:

I can't remember how they did the death certificate 'cos I'm sure he hadn't been to the doctors, we didn't really want him to have a post mortem um...so again I sort of had to give permission to the GP not to send him for a post mortem. I'm beginning to think he must have seen the GP sometime earlier that day, that would be really, really strange that he'd been to the doctors or that the doctor had come to him because otherwise he would have had to, anyway we got round it and they didn't do a post mortem and they said he had probably had a dissecting aneurysm *[previously in the interview Eve has*

*indicated this as her initial view]* I said he probably had and everybody was comfortable with that (Eve).

Her narrative is characterised by some uncertainty and mystery in relation to the events preceding his death in that her story is incomplete with elements being unknown. This resonates with the literature which indicates that bereaved family members rarely remember the precise details of a loved ones death, what they remember are selected events that have some significance to them (Kubler-Ross 1969; de Hennezel 1997). For Eve there appears to be an ambivalence in the wanting to know but respecting her parents wishes, it was clear that she had never questioned her mother as to the precise sequence of events and reflected that it was almost accidental that she was at her parents home when her father died. She reflected that her mother and father were very private in relation to their declining health and almost protected her from the realities of their situation, her father she describes as 'not the sort to be looked after, a very private person' the thought of personal carers would have been troubling to him.

Reflecting on the story of her father I made the following, rather hesitant, comment that:

It's kind of quite interesting the personal bit you just talked about because your sensitivity about what palliative care can offer in the community seems to link very closely to that about the social side of caring and the kind of, the very practical caring aspects (Sally).

Eve's response indicated that she appeared to be especially sensitive to the burden of caring and the very practical and social aspects of being cared for at home, that for some individuals it works and for others it is not an option.

The contrasting experience of her mother's death appears to have enabled a subsequent professional approach that is more judiciously interventionist; early in the interview she describes her mothers care:

My mother was in hospital when she died after an operation for a second malignancy, possibly pancreatic and whether it was because I was a doctor or not but they were sort of kept on...they kept on with the intravenous antibiotics and the drips and the drains and

she was deteriorating and in the end I said how long is this going to go on for? You know you almost have to give permission to stop treatment so they did stop treatment and she died very peacefully in hospital *[after a long pause and without any prompting she continued]* So she suffered, she suffered a fair bit. In fact I suffered more when she was confused strangely enough, she was confused at times and when she was confused she was quite happy and I would go out into the dayroom and cry and when she wasn't confused she was actually quite distressed then so it was um (Eve).

The sentence ended here and Eve took some time to become less distressed and when returning to the story became less emotional, more matter of fact despite my attempting to stay with her feelings by asking:

So your experiences have been almost like the two opposites of how people live and die? (Sally).

This was largely ignored, almost an intrusion and she continued with her thoughts rather than responding directly:

I think she knew she was dying really ... it went on for long enough but it didn't go on for weeks and weeks and weeks (Eve).

I was interested to try to understand whether these personal experiences had changed her, she was certain that it had changed her but found it difficult to be clear as to precisely how. On reflection it was the death of a second parent, the being an orphan, that has had a major impact on her personally and professionally. For her this personal uncertainty is in contrast to her professional role where she is clearly in control and the decision making rests largely with her. She describes a clinical situation of a woman with advanced cancer who wished to die in hospital and requested admission; where as a physician her natural decisions to instigate active treatment were modified clearly by her mothers' experience and the patients clearly articulated choice:

When she *[the patient]* went to the ward I was about to say can you put a drip up and then I thought who am I treating here? (Eve).

It was clear that her personal experience and knowing impacted on her clinical judgement and decision making, making her question the benefits, burdens and therapeutic intent of any interventions.

Eve also reflected on how irritated she became when people [*nurses in particular*] talk to relatives about how brilliantly they coped with family member's death and how they set themselves up almost as role models. This irritation appeared to enable her to pull back from some of the emotions the personal stories had evoked for her. Later in the interview she stated that she always felt, when she was a carer, she was treated like a doctor and for her that appeared to be helpful although she was not able to work out why. This is in contradiction to earlier statements that acknowledged this as being unhelpful in supporting her adaptation and grieving.

At the time of the interview with Eve, my father, despite increasing frailty, was still alive. At the time of writing he has been dead for just over a year and I am surprised by the emotions I felt when describing and exploring Eve's story. For me there is a shared experience in that although very involved with my parents I was unaware, until very recently, of the day to day burden of caring that my mother undertook. I was aware that my father was rather selfish and despite finding being cared for quite difficult, he was quite controlling and blissfully unaware most of the time of the impact that some of his symptoms and behaviours had on mum's levels of exhaustion. She has only been able to talk about her experiences since his death and appears to feel guilty that she is 'letting things out' now. I remember asking her many times during his prolonged illness how she was coping, she would always reply 'we're doing fine dear'. I do share Eve's view that being left with one parent is problematic in that you do worry greatly about the parent who is left alone. Mum's increasing physical and mental frailty seem unfair as it feels as though she ought to be able to have some quality time for her after being so constrained and compromised by caring for my father.

### **7.2.2 Flynn**

Flynn is in his early thirties and has recently become a Clinical Director; he stated this was by default because nobody else wanted to do the job. He is very organised, dynamic, enthusiastic and open. He has a young family of four children and spends his free time involved in sport. Before having children he was involved in dangerous sports but now his only risky sport is



ice climbing. He is very keen to see oncology and palliative care as seamless and feels the gold standard would be for consultants to be 'dual qualified'.

Flynn's clinical role is exclusively within the cancer centre, specialising almost exclusively on male cancers. The strategic and management elements of the role have had an impact, his clinical sessions have been reduced and he has become much more organised in his working day. The interview was characterised by a very clear focus and obvious political awareness. The distinctive elements of his experience relate to his specialist registrar training including a palliative care placement, this has given him a high level of expertise and competence together with a unique perspective in situating palliative care in oncology practice.

His age may also have had an impact on close family experience of death, on questioning the only close death has been that of a maternal uncle whom he hardly knew, all grandparents, parents and siblings are still alive and relatively well. He has had close friends and distant relatives that have died of cancer and reflects that some of them have been managed better than others but is certain that it has not influenced the way he uses palliative care, he reflects that it may be different if someone especially close to him dies. In relation to his personal and professional experience he is clear that the professional has had more of an impact and it is his training that has been the most significant:

I think the way I view palliative care was influenced by my training I've worked with good palliative care doctors who've been highly articulate and who were essentially good educators and you know I think that's admirable (Flynn).

He is the only oncologist, perhaps due to his age who, as part of his specialist registrar rotation, worked as registrar in palliative medicine before specialising in oncology. Asking him to articulate how that experience influenced his practice he describes it giving him a degree of insight into the role and activities associated with palliative care:

It's not just a narrow role of prescribing opiates or putting up a syringe driver for giving someone end of life care, it's a much larger role than that and it's a sort of psychological support and it's a sort of very holistic view

of how to manage someone with advanced disease (Flynn).

Additionally he acquired specialist communication and pharmacological skills together with a more holistic patient approach that he has incorporated into his practice as an oncologist, being very comfortable with counselling and psychological support himself. This is unusual as in most instances it is viewed as the role of clinical nurse specialists.

### **7.2.3 Greg**

Greg, in his late sixties, is now a part-time consultant preparing for retirement and has 'had enough now.' He is the second of the two participants previously known to me when I worked in clinical practice. He has been around and seen much change, not always for the better. He is very busy and the interview was constantly interrupted, largely due to his open door policy. Greg was very talkative and the interview was almost totally unstructured, probing was used to keep him on track with only limited success. Outside work he is very involved in amateur dramatics, this was apparent in his responses and slightly flamboyant non-verbal gestures. On reflection after the interview proper, (used here with his permission), he described himself as being 'the bridge, the glue between oncology and palliative care'. His parents did not shape him in any way, he believes he is very much his own man, their deaths, in their eighties, although sad were timely and did not cause him much distress although there are times he misses them being there.

Greg's uniqueness lies in his ability to locate current practice within a historical and political context. As a long standing consultant he is politically and professionally well regarded, he has been a past Clinical Director and is actively involved with a number of voluntary organisations. Greg appeared to use the interview as a way of reflecting on and evaluating his performance over the years. It also appeared to act as a catharsis. He was a little indiscreet almost vitriolic at times in relation to past colleagues, to political initiatives and to contemporary palliative care.

For me, one of the most revealing elements of Greg's interview was the narrative related to his clinical career choice where he describes in depth a very powerful critical incident when he was a senior house officer. This was for me a 'little gem' and is described in depth in the life-world discussion chapter.

This choice was validated by experiences during his SpR rotation which included a hospice placement and has never been regretted. This story, he revealed, was one that he had never described before to anyone in such detail. He had used elements of it before when teaching juniors but coming to the end of his professional career the whole story is imbued with a renewed almost cathartic or confessional significance in that it highlights for him the important elements of his clinical role, that there is a personal and professional responsibility:

It's a challenge but I don't think it's a bad challenge and I don't think if you're going to treat people who...with cancer...I think you have to...you should be able to do that because if you've seen them through the beginnings of the illness you should be able to see them at the end as well (Greg).

The very personal disclosure appeared to validate the use of the IPA and reflective life world approaches as a way of exploring experience, in that these approaches encouraged what was a more personal revelation that may have been missed if CIT was more dominant.

#### **7.2.4 Hermione**

Hermione, in her early thirties, is a fairly new consultant who has just returned from maternity leave. She struggles with her two specialist diagnostic groups', breast cancer which she describes as very well resourced, with a powerful patient group, and head and neck cancer which is almost the polar opposite with a very disadvantaged and almost marginalised patient group. Although her grandfather died over ten years ago, when she was a very junior doctor, the memories surrounding his death are very clear and especially relate to his loss of dignity and overwhelming distress when near to death. Her grandmother, she states, is 'fortunately' still alive. She feels this experience

has influenced her professional role especially, in that she might refer her patients to palliative care too early in an attempt to support them achieving a 'good enough death'.

### **7.2.5 Conclusion**

The oncologists were more different as a group than anticipated. Most valued palliative care but there was a degree of ambivalence as to its place in their patients' cancer journey. Their different career stages and personal experiences enabled a more idiographic description. For the oncologists it was more difficult to extrapolate their shared experience.

## **7.3 THE ONCOLOGISTS' SHARED EXPERIENCE**

### **7.3.1 Introduction**

As with the cardiologists the interviews were transcribed verbatim and analysed as discussed in Chapter 6. The comments from each of the oncologists were grouped together and linked to establish the themes derived and outlined below. Any unique or previously unidentified themes were also stuck to the flip charts for later attention. The oncologists were also given a number so that each individuals response was identifiable e.g. Eve = 5, Flynn = 6, Greg = 7, Hermione = 8. As for the cardiologists linguistic interpretation was undertaken by considering the specific use of language. Metaphor was the element of language focussed on, paralinguistic comments were annotated on the interview transcripts and are presented separately in Chapter 11.

As outlined earlier the subordinate themes reflecting the experience of all the oncologists were:

- Patterns of referral
- Perceptions of palliative care
- Complexities of decision-making
- Resourcing
- Specialist clinical knowledge
- Personal experience
- Models of service delivery and provision

### **7.3.2 The shared experience**

In response to the opening question 'Do you ever refer your patients to specialist palliative care services'? The oncologists all replied 'Yes', their individual responses varying from 'frequently, often, several times a week and lots and lots'.

Eve, a well established consultant, reflected that she was probably referring less often, in considering why this might be she indicated that it was either because they had already been referred without her knowing, as many patients are not routinely seen by oncologists, or it might be just one of those things. Reasons for referral in her interview identified some inconsistency of thought. Initially Eve indicated that referral was instigated for managing patients' increasing physical and psychological symptoms, but by the end of the interview when re-visiting the benefits of referral and linking to her experiences, less tangible reasons emerged that were more linked to family dynamics and concerns. She states:

Patients with young children I would have a pretty low threshold for sort of referring on you know there's often things to be worked through there and some of them actually ask for it, what shall we tell the children and that sort of thing so they might they may not have a lot in the way of physical symptoms but you just think there are, we need to give them a chance to do things, write things, leave things (Eve).

For Eve this demonstrates a 'sixth sense' of knowing and clinical judgement, (clinical intuition) by identifying the need to facilitate people with putting things in order, it is a more family-centred, holistic approach.

On a practical level, Eve was more likely to refer in the geographical area where she has an established relationship with the palliative care team, the Macmillan nurses. It is usually part of the out-patient consultation due to ease of access and is usually for community support. She also identifies that referral is more important for people who seem a bit more upset than would normally be expected, are perhaps not coping themselves or where the family are not coping, for people who are perhaps more isolated, have a poor

relationship with their GP or feel angry about things. As discussed in the previous chapter these reasons are contradictory to the reasons for referral outlined by the cardiologists which were predominantly to support coping families.

For some people palliative care has limitations and does not always have the answers, she reflects on a man who appears stuck in his responses and adjustment to his disease progression believing he is beyond what a Macmillan nurse can deal with now and needs a psychiatrist, 'he's stuck and he's frightened'. She acknowledges that his pre-existing problems have impacted on his current situation recognising that he was probably strange even before the diagnosis.

Referral is compromised by patients and families in that some people do not want the Macmillan nurse to visit, often this relates to an actual or perceived bad experience of somebody they know. Eve describes a patient's apparent unhelpful experience, he told her that when the Macmillan nurse comes all they do is talk about the fact that he is going to die and he very definitely did not want them to discuss this. Eve is able to see the professional perspective in that he is a man who is going to die and he has got a young family but also seems to appreciate his autonomy in refusing input from palliative care.

Flynn, one of the two younger consultants interviewed, sees palliative care as an integral part of cancer patient management. Initially Flynn was surprised by my question in that referral was almost routine for him; further exploration identified that in reality there were specific triggers or 'red flags' that prompted him to refer. Referral is usually made for people with difficult symptom control that is beyond his and the teams' scope and expertise in management; this encompasses both physical and psychological symptoms.

All the oncologists believe referral to palliative care is of benefit at the early stage of cancer treatment for symptoms associated with treatment, for dysfunction and chronic pain and for advice and support; at the time of diagnosis of a non-curable cancer or when the individual newly diagnosed has

a dual diagnosis with pre-existing co-morbidities and multiple pathology; also later in the disease trajectory, when the person has advanced disease and symptom problems but remain mobile. Referral is also indicated to support the family. Other support issues relate to the adaptation from a curative cancer to a terminal cancer or following an acute event for example, when as Flynn describes:

Something devastating happens like spinal cord compression so they are then paraplegic and suddenly go from being self caring to being nursed dependently (Flynn).

The patient is not terminally ill but their adaptation requires multidisciplinary input to support the massive, sudden shift and change in outlook.

For patients and professionals referral signals a change in approach and outlook, the ideal being to refer before a 'crunch point', to enable the establishing of a relationship with the palliative care team, to support proactive planning by anticipating current and future care needs, the goal being to improve the quality of life.

Flynn compares his professional experience to that of his colleagues:

I suspect that non-oncologists, some of the general physicians or surgeons do see palliative medicine as a way out for dealing with patients with sort of bad diseases or terminal cancer so that they may also be reluctant to do it, but I mean from my point of view it's a simple part of cancer management (Flynn).

Hermione's responses in relation to explicating factors for palliative care referral reflect a degree of similarity with those of Flynn, both are relatively new consultants and of a similar age. The two major differences between them relate to their professional training pathways and Hermione's personal experiences of a close family members death.

For Hermione the bonus of a palliative care referral being that:

I can then concentrate on managing the treating of the cancer and allowing symptoms to be controlled elsewhere (Hermione).

Palliative care for her, and is reflected in the other oncologists experiences, is appropriate to facilitate improvement in patients' symptoms and a good death. Family factors influence referral. The ideal timing being that palliative care services should be involved early enough to establish a relationship that enables family and psychological support which may include day care. Referral may be especially useful for people with a young family and children, to help them with talking to the children and involving them thus hopefully ensuring they have good memories. For a husband not coping with his wife's diagnosis and needing counselling services. Palliative care can offer a 'safety net' being the first point of contact for the family in avoiding panic, information giving and facilitating help, acting as a bridge between services.

Greg describes his unique clinical and historical relationship with the local and national palliative care services that impact on his referral practices. Greg links reasons for referral to the type of service available, inpatients are referred to the hospital palliative care team primarily for advice on their symptom control, specifically pain, dysphagia, discomfort and anxiety. For individuals he sees in outpatients a community referral helps in assessment of home care needs and support at home. The final group are those he refers for in-patient assessment:

Who we feel have got a limited life span and who we feel would benefit from in-patient assessment, intensive assessment of their symptom control needs with a view maybe to getting them home, but not always (Greg).

Again he agrees with his colleagues that referral is not always made for patient need, it is often related to the needs of relatives. Particular motivators relate to younger patients, for families with young children, for anticipatory grief work and holistic support.

Greg and Flynn describe referral as a two way process providing a clinical example of a cancer patient being referred back to his care for active cancer therapy. For Flynn:

The interface with and between palliative care and oncology is a good two way interface it's not just us



dumping stuff onto them and I think we have a constructive relationship (Flynn).

The oncologists' perceptions of palliative care, as explored in the interviews, were linked to its perceived advantages and disadvantages for their patients and its impact on their own clinical role. For Eve and Greg both nearing retirement, their responses were mediated by the evolutionary historical and clinical context that has influenced their practice in the last thirty and thirty-six years respectively. For Eve a 'good death' depends on family carers and the place of care. Palliative care facilitates a better death, a 'good enough death'.

For Hermione, palliative care makes her life easier she describes it as a 'safety net' that gives her patients a bit of control, it acts as a 'go between' between patient and GP, patient and hospital, it lessens panic about who to contact and where to go. She likens the palliative care 'safety net' to the 1984 Film 'Ghostbuster's' whose tag line 'Who ya gonna call, call Ghostbusters', in that it leaves no doubt as to who to contact. Eve, Flynn and Greg also use the phrase 'safety net' in relation to its advantages for patients in accessing urgent care, supporting choice and facilitating decisions. The universality of the phrase 'safety net' used by all the oncologists suggests that they all recognise the uncertainty and unpredictability of their patients situation and that they as a professional group do not have all the answers.

For all oncologists palliative care is synonymous with place of care, which can exist in a variety of places. Hospice care is associated with appropriate medication and a peaceful death, it offers respite, rehabilitation and terminal care in a beneficial and peaceful environment, supporting holistic, expert, seamless care. Palliative care at home identifies problems at home, enables professionals to understand the realities of the patients' situation often associated with poor mobility and difficulties with the home environment. Community services provide better access to patients' realities of daily living. Most of the oncologists acknowledged that patients living at home are different from patients in hospital.

Some oncologists hold a negative view of palliative care. Flynn stated that in the past, palliative care was viewed with antagonism and suspicion by many oncologists. They are different specialities with different ambitions, Greg believes that there always have been and currently are lots of 'empire builders' in palliative care, it 'has grown like Topsy' but he is unsure what palliative care wants from them [oncologists]:

There's been another change now um and I think I feel there is a certain lack of clarity about just what patients they are prepared to take because they have been oscillating like a pendulum one of the problems is that they will often not take patients if they seem to be a chronic problem then they don't want to take people if they are only a week away from death so where does that line come? (Greg).

Some patients feel oncologists will no longer see them when there is no more active treatment, for Greg this is not the case 'if caring for people with cancer I see them from beginning to end'. All oncologists confirm that there are many myths and misperceptions held by patients about palliative care that it is the end. From Hermione's experience:

A lot of people are reluctant to have palliative care because they see it as the last. This is it I'm dying tomorrow. If you talk about symptom control people think about dying and as soon as you mention the word hospice then they think that's it the end (Hermione).

They reflect that for patients and families the word hospice equates with death, it is a 'big block' historically negatively associated with cancer care, that 'you are going to die, it is a one-way ticket'.

I wondered whether this was still the case in 2011 and elicited this response from Hermione:

I think so, the fear on their face and even starting someone on morphine you will see the patients face 'I don't want to go on morphine' because they associate morphine still with dying, the end of the road (Hermione).

For Flynn:

The prime problem is you still mention palliative care and they've [*either*] never heard of it and some who say 'oh God, does that mean I'm going to die?' (Flynn).

Often their response is influenced by their past experiences of family, friends and neighbours who for example went to the local hospice and died there. Flynn sees his clinical responsibility as 'disabusing them of that idea'. Unlike Hermione, he believes perceptions are changing but very slowly.

Greg believes that in the narrow geographical area he works, people always go to the deaths section in the local paper, deaths in the hospice colours their views about it, leading to resistance as a place of care. For Eve, Greg and Hermione it is the name palliative care that is problematic, the word cancer appears to generally evince less fear in their patients than the prospect of palliative care. Flynn agrees that there are negative perceptions of palliative care held by his patients, generally based on historical perceptions; these negative views are also held in relation to cancer:

We're dealing with history with cancer management all the time, patients have got major preconceptions about chemotherapy and chemotherapy side effects which are historically determined. They've got major preconceptions about what happens to patients with cancer based on sort of forty year old clichéd model that patients with cancer lose their hair, vomit and die (Flynn).

Historically, palliative care has been linked with dying from advanced cancer. In relation to other diagnostic groups the difficulties of non-cancer palliative care relate to different and uncertain disease trajectories, the establishing of a prognosis and 'diagnosing dying'. In relation to establishing an end of life prognosis Eve states that it is generally easier with cancer, reflecting on her clinical experience she suggests prognostication is easier with some types of cancer than others, for example lung cancer, rather than ovarian and brain cancer:

Lung cancer patients once they start to deteriorate tend to deteriorate more rapidly but some of these poor ladies in and out with intestinal obstruction with ovarian cancer

are not well enough to go home but not actually quite dying, they can have a rather long terminal phase (Eve).

Hermione, in support, confirms that it is easier for lung cancer rather than her clinical speciality of breast cancer. She believes prognostication also occurs at the time of diagnosis, often inappropriately. For example Hermione states if you tell someone they have cancer they think they have six months to live there is this perception that 'I have cancer I'm going to die'. Although this is not always the case:

It's actually easier (*compared with COPD patients*) to give a positive prognosis to cancer patients because they have already thought the worst and then actually saying well no I can't cure you but with treatment if you respond you could actually have extra time which is what they weren't expecting really (Hermione).

The cancer trajectory is variable. Eve recognises that some cancers have a long terminal phase with poor quality of life whilst for others the disease progression can be very rapid. Greg concurs that the trajectory is uncertain in that palliative care patients have acute events, pre-existing problems impacting on the palliative phase and there is always unpredictability in the timing of dying. It may not always be the cancer that precipitates the terminal event. Hermione's clinical experience reflects this by her assertion that a lot of patients do die of something other than their breast cancer. This supports the different perceptions of cancer which is often related to its perceived curability.

In the oncologists' stories the difficulty is often related to chemotherapy which sometimes delays the inevitable, that for some people cancer behaves almost like a chronic illness and there is a shock when all treatment options are exhausted and a secondary cancer is present. For patients it is like being told they have got cancer all over again, going back through the grieving process and psychological adaptation.

Flynn and Hermione compare the disease trajectory and prognostication difficulties in cancer with other conditions. Flynn reflects:

Although people can be disabled with cancer a lot of patients are actually fit and mobile and not too dependent till the last few weeks of life, whereas someone with a neurological condition there may be months and months of progressive debility and intense nursing and its a different disease with different needs (Flynn).

Hermione concurs, being aware that the prognosis of certain other types of disease is actually far worse than cancer, for example:

If you've got type 4 heart failure or you've got severe COPD your prognosis is less than a year but you don't have access to all the support groups, all of the charities (Hermione).

Greg appeared amused by the cardiologists view that cancer prognostication was relatively straightforward, his response being 'God if only they knew (*laughs*) perhaps they'd teach me how to do that'. Reflecting on clinical examples in relation to DS1500 forms (additional allowances made to individuals with a terminal condition and a predicted prognosis of less than six months):

I regularly get 'phone calls from the DHSS [*Benefits Agency*] along the lines...you filled this form in about four years ago, the patient is still alive, do you want to change anything? (Greg).

Prognostication in cancer, as discussed earlier, is also uncertain and imprecise. Eve believes that cancer patients are usually more aware of their situation, accept the prognosis and usually move on. Hermione concurs 'for lots of patients a poor prognosis may not be a surprise'

Often family influences conflict with patient choice at the end of life, the following situation is perhaps unusual as Eve reflects:

I saw somebody two to three months back and she came to clinic and she was nearly dead and I thought my goodness what are we going to do here so I rang the hospice and said have you got any beds and they said no shall we put her on the waiting list and I said no there's no point in that she and the family wanted her to go home and she said "but I don't want to go die at home, I want to die in hospital" and it was a very caring family and they would have managed as it really wasn't

going to be that long and she was absolutely definite that she wanted to die in hospital and miraculously there was a bed. Yes somebody hadn't turned up to come in for chemo and there was a bed and this was about lunchtime and she died about six o'clock the following morning. It was very imminent and yes it could have been more imminent than that, I was almost surprised she lived that long it was a good death in that her family were there but they wanted her home (Eve).

The literature suggests most people would choose to die at home but for a small, significant number the choice is to die in hospital. Reason perhaps relating to their perceptions of not being a burden to the family or that it is a safer environment for care.

In relation to resourcing, the oncologists were all able to identify gaps in service provision for their patient group. Although universally it was felt that breast cancer patients were those who received most resources. For Eve it was simple to identify generic needs, more hospice beds, more home care, and more personnel. Flynn commented that there were 'finite resources', that services were under-resourced even for cancer; again identified needs were for more beds, more staff and, specifically for him, anaesthetic pain control. Hermione stated there were not enough physicians or nurses.

In exploring the extension of palliative care to non-cancer patient populations it was universally felt that it would adversely impact on the palliative care of cancer patients. Greg from his length of experience, was clear that 'this was how it was originally meant to be' although on a practical level thought it would disadvantage cancer patients. Non-cancer palliative care requires different skills and would be more demanding on nurses.

Personal experience of the death of close family members was shared in depth by both Eve and Hermione. Eve's experience has already been described earlier in the chapter. From a personal perspective, Hermione describes her grandfather's death over ten years ago, when she was a junior, as being very present for her always. It was a badly managed death at home,

largely due to her grandparents' choices for 'normality', not wanting sympathy or any external help:

It was horrendous and so that definitely colours how I perceive things, for me going through the experience that I've gone through that's why I believe palliative care should be involved a lot earlier than we involve them, because that was just such a disaster. I still remember it and I still remember the worst bits rather than the good bits (Hermione).

She describes him being opiate toxic and hallucinating, in agony and in distress, she believes this made her realise that care at home is 'hard work'. This has influenced her professional role in that she strives to be open and honest with dying patients, giving patients the options and attempting to deal with the root cause of their problems. The personal for her also clearly impacts on her professional role in that it: 'definitely colours the way I feel about things and whether it's appropriate or not I don't know'. Perhaps as a consequence she now 'refers too much and too often', although there is no evidence from her interview to suggest this is the case.

Flynn and Greg alluded to the personal but focussed on their early post-registration medical careers as having the most powerful impact. The time gap between their experiences was thirty years but there were clear similarities in that their career choices were influenced by a particular senior doctor who was perceived as a positive role model either as a clinician or teacher. Both role models displayed professional knowledge and skills that Flynn and Greg emulated and valued in their own practice.

Flynn comments:

I've got, you know, close friends or relatives that have died of cancer and some of them have been managed better than others clearly, but that hasn't influenced the way I've used palliative care (Flynn).

It is his training that remains the most significant:

I think the way I view palliative care as in my training I've worked with good palliative care doctors who've been highly articulate and who were essentially good educators and, you know, I think that's admirable (Flynn).

He is the only oncologist, perhaps due to his age, who as part of his specialist registrar rotation worked as registrar in palliative medicine before specialising in oncology. Asking him to articulate how that experience influenced his practice he describes it as giving him a degree of insight into the role and what palliative care can offer:

It's not just a narrow role of prescribing opiates or putting up a syringe driver for giving someone end of life care, it's a much larger role than that and it's a sort of psychological support and it's a sort of very holistic view of how to manage someone with advanced disease (Flynn).

This insight is unusual, it is one that would be acceptable to palliative care specialists, and is clearly at odds with the narrow perspective of palliative care evidenced in the interviews with most of the cardiologists.

Additionally, Flynn acquired specialist communication and pharmacological skills together with a more holistic patient approach that he's taken to his practice as an oncologist:

I haven't used palliative care services much personally for counselling or psychological *[support]* this may be because I feel very comfortable with it myself (Flynn).

Greg's professional experience related to his choice of career, a 'little gem', is described more fully in Chapter 10.

All the oncologists indicate that geography and rurality negatively impact on peoples' access to both oncology and palliative care services. Services are very city centric, rural services being less robust. The geographical variation in services is analogous with historical service developments being charity led whereby affluent areas are more likely to benefit. The location of the local hospice is not ideal and is related to historical political and professional influences. The ideal model of service provision would be seamless and fully integrated with oncology services not as a separate speciality, facility or site.

Patient variables impact on service provision and delivery. Flynn provided reflective examples to corroborate the existence of disadvantaged groups who



he suggests should be the types of patients palliative care should focus on: those with secondary disease who are not radically curable, those who live alone lacking social support, have a dysfunctional family and 'bad disease'. Gaps in service provision relate to those who are chronically ill with cancer and managing to live normally, they are an excluded group with no services.

When asked whether patient age might be an influencing factor Flynn replied:

Yes it does I mean if someone's is, sort of, elderly and they've got advanced cancer then they may have co-morbidities so they may have diabetes, heart failure or whatever, that does influence it and also you know that if in general, if things go wrong they'll tend to decompensate more quickly you know. But the converse is true if you've got a twenty-five year old guy with incurable cancer and he's got a three month old baby and a young wife you know they've got their own special needs, you know life is just taking a terribly tragic turn for the worse. But whereas an eighty-five year old may be quite philosophical so there's a separate load of issues. It might not be so much in the physical side but you know they [*younger patients*] clearly need a lot of psychological support almost certainly (Flynn).

Other factors (identified in the literature review) such as gender, ethnicity and pre-existing medical conditions such as learning difficulties or mental health problems were not mentioned explicitly.

### **7.3.3 Conclusion**

Greg, for example, is very aware of the close relationship between the two specialities stating that 'palliative care could not exist without oncologists'. All the oncologists acknowledged that cancer patients are the most common, and perhaps, the most appropriate palliative care patient population. Referral to palliative care is made easier in many situations by the more predictable cancer trajectory and easier identification of end of life.

In some instances the roles of oncology and palliative care seemed almost symbiotic in that both advantaged the other during the patients' journey. Their stories demonstrated a more holistic perspective and a deeper awareness and understanding of the patients' predicament.

## **CHAPTER 8 - THE OLD AGE PSYCHIATRISTS**

**Physician's won't say no, they just say go, go, go, go. (Ian).**

### **8.1 INTRODUCTION**

This chapter will provide a descriptive account of the experience of the consultant old age psychiatrists', it will initially present short biographical details of both before describing their unique experiences. The second part of the chapter will describe the patterns and connections between them as a dyad in an attempt to present their shared experiences.

Two old age psychiatrists, Ian and Mair, were recruited to the study. The reasons for this have already been explained. As a dyad they were only homogenous in relation to their clinical speciality and their perceptions that dementia end of life care, for them as professionals, is much less stressful than 'suicide risk assessment' and dealing with the aftermath of a known patient's suicide. The geographical area in which they practice is mixed with metropolitan, urban and rural populations and evident socio-economic deprivation. In most other respects they were different with unique opinions and perspectives.

### **8.2 THEIR IDIOGRAPHIC EXPERIENCE**

#### **8.2.1 Ian**

Ian is in his mid forties, he has been involved with old age mental health for about fifteen years. He used to be a Clinical Director but is now more involved at the strategic and organisational level with audit, governance and Fitness for Practice issues. He is embracing the use of reflection in his work as a way of validating his level of professional knowing and as a means of peer review in managing the poor performance of clinical colleagues. Ian dresses very casually and is very engaging and collaborative, this belies the strength of his views and his certainty that he has a high level of palliative care knowledge being largely self taught. By his own admission he does not suffer fools gladly, being acutely aware of litigation and the media's pernicious impact on health care practice. He states that clinically, palliative care

patients are the least stressful of his patient group, being 'not really much of a concern'. Suicidal patients and their impact on the team are more troubling. Ian works in a metropolitan and urban locality based clinically in a large district general hospital and supporting the surrounding community. Strategically he acts as a clinical, professional and medico-legal advisor to a number of local and national organisations.

The uniqueness of Ian's story lies in his self confidence in relation to his own performance. He describes a self development process that has skilled him to an effective level, he was able to point out during the interview my inadequate knowledge 'you would not be right' in relation to management by antipsychotic medication. For him, the challenges in end of life care are those set by relatives who may have 'unreasonable or uninformed' expectations and those related to the medico-legal intricacies of withholding and withdrawing of interventions. His role has evolved as his team has got larger and he appears to have a slightly distant relationship with the continuing care teams, almost fulfilling the role of 'trouble shooter' being involved when his colleagues have exhausted their therapeutic options or in relation to family care:

I would only get involved when that *[the relationship]* had seriously broken down, where the nursing staff haven't been able to maintain a rapport and they were getting criticism which we're poisoning people (Ian).

Ian describes himself as at his professional 'zenith' *[his word]*, believing that all his talents are being exploited to the full; he appears very confident in his clinical skills especially in relation to palliative care. His interview is polemical in parts particularly in relation to the investigations undertaken following an in-patient suicide and the impact on the clinical team. Ian identifies a clear professional role and responsibility:

I see a need to defend staff against the horrible powers that be, including the public (Ian).

His approach feels somewhat combative both in how he spoke and in the content of the interview especially the elements related to dealing with complaints and investigations, perceiving his role as to 'protect other people'.

By contrast he is aware that he adopts a more conciliatory tactic in discussing resuscitation decisions with family members:

If the family weren't in a position to make a decision then I wouldn't make a decision, the default being that the patient would remain for resuscitation which isn't easy and probably is not in the patients' best interests in the medical sense but in a wider sense I think it is (Ian).

The apparent duality in Ian's interview demonstrates the tensions associated with clinical practice, especially in psychiatry where increasing investigations and litigations influence practice perhaps making practitioners more cautious and potentially vulnerable. Ian's interview reflected the myriad of roles present in his working life. The content of his interview was an amalgam of styles with him appearing alternately charming, pragmatic, confident, pugnacious, reflective, self critical and questioning. The most telling line in the interview being: 'I suspect I'm a bit more vulnerable than I would like to think'. When pressed to explore this further he admitted to no personal experience of death, but feels that he may not be as prepared for it to happen in his personal life as he believes himself to be and this potentially makes him vulnerable.

### **8.2.2 Mair**

Mair is in her mid sixties, a Welsh speaker whose first language is Welsh. At the time of the interview she had a terrible cold and was compromised by this. Working in a very circumscribed geographical area, Mair felt that she and her team had developed a good service for their patients from diagnosis to death. The major concerns relate to patients with a dual diagnosis and ethical issues related to withdrawing food and fluids. She has developed her own knowledge base in relation to palliative care but was very clear that all of her professional life is influenced by the strength of her religious faith. Mair is the only participant who made reference to her strong religious faith, as a practising Christian this influences 'how I am and who I am'. It is the suicide or attempted suicide of her patients that is the most upsetting to her. The death of her father she describes as timely, 'sad but right'. Retirement for her

is very close and a real opportunity for doing new things, she describes herself as 'winding down'.

In contrast to Ian, Mair was more self-effacing and reserved in relation to her expertise, she did not question her skills and provided evidence that her therapeutic interventions are appropriate, but she was cautious in her descriptions. Alone among the ten participants Mair was very open about the strength of her Christian faith underpinning her professional role. Especially in relation to death and dying she appeared almost fatalistic, adopting a matter-of-fact stance: 'there are worse things than dying'. Her role was clearly about supporting patients and families with the process of dying which for dementia patients 'can be quite a long process'. The practical tensions of care relate to her unit not providing long term care and therefore many patients end their lives in nursing homes where she has limited clinical jurisdiction:

We wouldn't be doing the terminal care, in the nursing homes the GP's would be doing it, but, you know, we just do the mental state [*the mental health care*] (Mair).

On reflection she acknowledges that for her patients and their families dying in a nursing home would not be the preference, but resources are limited and that as a consequence is the necessity. This dilemma was not articulated by the other consultant groups and only superficially alluded to by Ian.

Mair works and lives in a rural community where she is responsible for developing and delivering a locally driven service in meeting the mental health needs of the elderly population. She works in the community and is based at a small cottage hospital where her in-patient beds are situated. She was born in this community, has been well established as a medical consultant for almost thirty five years and is looking forward, albeit with mixed emotions, to her retirement.

The characteristics of Mair's interview may (apart from her Christian faith) appeared to be influenced by her career stage, imminent retirement, the geographical locality which is more rural with a consequent slower pace of life and her gender which implicitly may have encouraged an apparent 'softer'

less dogmatic approach compared to that of Ian. On reflection and re-listening to the interview a number of times, this apparent softer style was underpinned by dialogue that presented a clear, almost determined focus.

### **8.3 THE PSYCHIATRISTS' SHARED EXPERIENCE**

#### **8.3.1 Introduction**

As with the cardiologists and oncologists the interviews were transcribed verbatim and analysed as discussed in Chapter 6. The old age psychiatrists were the least similar in their clinical approach to palliative care, the stage in their careers and in gender. The analysis of their interviews mirrored that undertaken for the oncologists', any unique or previously unidentified themes were also stuck to the flip charts for later attention. The psychiatrists were also given a number so that each individual's response was identifiable Ian = 9, Mair = 10. As for the other participant groups, linguistic interpretation was undertaken by considering the specific use of language, metaphor was the element of language focussed on, paralinguistic comments were annotated on the interview transcripts and are presented separately in Chapter 11.

The following list of subordinate themes reflecting the experience of both the psychiatrists was smaller and perhaps influenced by their lack of homogeneity and the fact that there was only two of them;

- Patterns of referral
- Perceptions of palliative care
- Complexities of decision-making
- Specialist knowledge
- Personal experience
- Models of service delivery.

#### **8.3.2 The shared experience**

Ian's responses to my interview questions were wide-ranging, at times it felt like he was almost having a reflective, exploratory dialogue with himself. He presented himself as very emphatic, controlling and directive. When we met he stated 'that he didn't suffer fools gladly'; he certainly corrected my knowledge deficits in relation to aspects of psychiatric care. My role was mainly as a prompt in enabling further elucidation of his experiences, it was the longest interview with the least dialogue from me. Ian had been a

participant in a number of research studies so for him this experience was familiar.

Mair has never been asked to be a participant in a research interview before and saw it as an intriguing experience and appears keen to keep in touch in relation to the 'finished product'. Mair at the time of the interview was suffering from the consequences of 'flu, had a very hoarse voice and an irritating cough which interrupted her responses. Despite this Mair was keen to go ahead but on reflection this may have shortened the interview.

Ian replied 'Yes' to the first question regarding referral of his patients to palliative care services, without even minimal prompting offering to put 'some context' on his answer. In the early days of the relationship with palliative care he reflects:

We had some exceptionally difficult patients during that period um and I think we worked out a number of tactics sometimes things which they [*the palliative care team*] hadn't done before themselves...sort of different tactics (Ian).

It was almost like a shared approach to care, which appears to have evolved over time and as relationships developed into a more self sufficient model care.

His evolving clinical role means that he now has less contact with the continuing care wards where most people with advanced dementia are cared for, thus he refers less than he did five years ago. His earlier clinical role made the acquisition of clinical skills in relation to palliative care important. Describing himself as being largely self-taught he has built up over the years quite a lot of experience of the things that palliative care can and will do. He described the process of having tutorials and updating with the palliative care consultants that was evolutionary:

If you focus on the group I used to refer, [*it*] would be the continuing care [*wards*], the advanced and profound dementias there um...and I have to confess I made some notes, some records and just sort of learnt what they would do and there is probably a regular pattern;

the things that would usually be required, the things that would usually be required, the things that would usually work. I just did what they would normally do and it would either work or it wouldn't – in the small proportion of cases where it didn't work we'd ask them for assistance (Ian).

In response to probing he describes his level of expertise as at least moderate a clinical example being:

We've got somebody in [*the local hospital*] she's a very elderly woman with advanced dementia, the concern is her pressure area care, then we end up with wound issues that may relate to pain which she can't articulate. So how do we balance the pain? Usually it's fairly simple from our point of view to maintain analgesia and anxiolytics (Ian).

Ward link nurses, also educated by palliative care, have a moderate level of palliative care expertise, they offer psychotherapy and counselling for family members and are responsible for establishing and maintaining relationships. Ian sees himself as the 'drug merchant', he becomes more involved when relationships break down and when there is the need for medico-legal stuff in relation to hydration, nutrition and resuscitation. He describes his role as 'making sure things are kept tidy'.

Currently the SPC team are primarily used as a telephone resource for advice on medication management, drug therapy, pressure area care, hydration and nutrition. Face to face contact was limitedly required and related to practical skills, such as syringe drivers and wound care and specific symptom problems especially agitation and pain. Less often a referral is made to elicit a second opinion and to avoid a complaint when challenged by the family. Unlike the cardiologists, Ian and Mair demonstrate a respectful and reciprocal relationship with palliative care, Ian comments:

We wouldn't call them unnecessarily and in exactly the same way they manage the vast majority of their patients with mental illness...the only questions they ever ask is about follow up (Ian).



There has been an apparent sharing of clinical knowledge that appears to have empowered both specialities.

For Mair, her contact with the palliative care team is only made for patients with a dual diagnosis, particularly a difficult cancer diagnosis together with the usual dementia situation as in the case of a lady whose dementia was very early on but she had 'a very massive throat and neck cancer'. This lady, because of her mental state, could not be managed elsewhere but the head and neck cancer was 'very alarming' to her and the wider team. Mair's choice of words clearly indicated the distress of the situation. Ultimately, this lady went to the local hospice where a reciprocal relationship was established, the old age psychiatry team helped the hospice deal with her mental state and they in return dealt with her complex physical needs, in particular her intractable pain.

Other factors that may predicate referral relate to the management of other complex symptoms, Mair's comfort zone relates to palliative care for those with dementia and cerebral vascular disease. Her relationship with the palliative care team appears to be based on clinical need, there is no regular contact and she was unable to name her palliative care consultant colleagues. Mair describes the current distinction between mental health and physical nursing as making palliative care in dementia more difficult due to the myriad of patient and family needs which neither speciality appears able to meet. For Ian this issue is resolved by the link nurse model of care whereby mental health nurses have received education in the core principle of palliative care thereby acting as a resource to their clinical area.

Mair's recent attendance at a 'Medicine in Psychiatry' course included an update in palliative care session which validated her knowledge and was confidence affirming. Palliative care she uses occasionally as a resource or as trouble shooters, she describes her relationship with palliative care as being 'knowing a man that does, but doing the basics yourself isn't it'. The basics for Mair include decision making in relation to withholding and withdrawing treatments and intervention, for example Cardio-Pulmonary

Resuscitation, food and fluids. Clinically Mair sees herself as a 'safe pair of hands' her focus being the clinical care and support of her patients, their families and the staff caring for them who she describes as 'almost like family'.

Both Ian and Mair appear secure and comfortable in their specialist clinical knowledge in relation to dementia. This knowledge appears to impact on their perceptions of palliative care, in particular its limitations and benefits for their patient group.

For Ian, dementia is a terminal condition at diagnosis:

It's over a longer period perhaps than some other terminal illnesses but it's still a terminal illness (Ian)

Establishing an end of life prognosis or life expectancy estimation for people with advanced dementia is problematic:

I don't even try I've been wrong much too often to be comfortable, when relatives ask me about it I say 'for your average Alzheimer's illness the course will be between eight and twelve years'. If they are younger paradoxically at the age of onset it will last longer by and large the prognosis at the end of life is dependent on physical health (Ian).

He describes his clinical heuristic of dementia:

I've got a very, very rough rule of thumb, some mild dementia is obvious enough for people to notice but not pick them out of a queue in Tesco or whatever, moderate we've got major problems but we're still up and about, severe we're not up and about anymore and profound is we're not very far away from the end (Ian).

Mair concurs that:

Dementia is a terminal illness but it's not an acute event, end of life really can be a quite long process here (Mair).

And in relation to prognostication:

People will say 'how long' and that's something we can't say you know, I don't ever say time scales and people will ask me for time scales much earlier on in the dementia and you know I tell them the national averages

really less because everybody's different and they are just an average (Mair).

Of the two participants it is only Mair who discussed the use of the last days of life pathway as facilitating care at the end of life for her patients. The pathway validates her practice especially in end of life decision making and the tick boxes act as a reminder and focus for specific aspects of care for example agitation, pain and excessive secretions but it is occasionally unhelpful:

You get it slightly wrong and you put somebody on the pathway and they rally and that's a bit distressing (Mair).

Mair describes a particular incident of a lady being admitted for respite care who was, on assessment, clearly nearing the end of her life. She was put on the pathway but took almost a month to die, the pathway was appropriate in her case but its disadvantage being that it suggests to families a very short time frame which is rarely the case in dementia. Clinically Mair tends to err on the side of caution, telling people things are not very good and if improvement occurs it is a bit of a bonus. Her religious faith enables the pragmatic stance that we have no control over death and dying that: 'It's in God's gift isn't it' the implication being that living and dying is preordained.

From Ian's perspective for people with dementia it is the co-morbidities and predisposing factors that impact on the disease trajectory and precipitate the terminal event, these might include a chest infection, haemorrhage, stroke, septicaemia and myocardial infarction. Less frequently patients simply die of their dementia. This is also confirmed by Mair's experience and links to the experience of the cardiologists' who describe acute events as being a 'tipping point'.

For Ian, caring for patients at the end of life is not difficult, relatives make it difficult. Influenced by the media they make unreasonable, uninformed and prejudicial demands especially in relation to medication. Mair's relationship with family members appears less problematic, this is likely to relate to her role as being more involved with the continuing care wards. Dealing with complaints for both is an increasing part of their workload. Both make

reference to the lack of complaints related to end of life care as being evidence for it being 'a job reasonably well done'. Mair states that most complaints relate to falls, poor pressure area care and suicide. This statement is surprising in that common symptoms at the end of life are related to poor mobility and increasing frailty often leading to the development of pressure sores and falls. Neither Mair nor Ian made this link or indicated that any complaints received were related to poor care at the end of life.

Ian describes his exposure to personal experience of death and dying as minimal, his grandmother died when he was a teenager and she just 'disappeared' with her death being hidden from him. Currently having 'four surviving parents and step-parents and in-laws so everyone is still going' he is aware that this situation is unusual and short-lived and as a consequence is unsure how it will be when death touches him more personally.

He tells a number of professional reflective stories, critical incidents, related exclusively to death and in particular modes of death which appear to have offered proxy experience, influencing his career pathway and legitimising his public profile. Working in intensive care as a hospital cleaner prior to starting his undergraduate medical training he witnessed an unsuccessful resuscitation, the experience was 'utterly surreal', and on reflection he remembers that it was very matter of fact and not like the television which had been his only previous experience.

The next event was when, as a medical student, he was involved in following a gentleman through his diagnostic journey by witnessing an endoscopy, a routine procedure. He remembers that his consultant: 'sort of knew, had a sixth sense that something was going to go wrong'. The patient arrested in recovery and died which was not supposed to happen. Ian returned to the ward (where he had worked as a cleaner) and the nurses recognised his distress:

I was a bit shaken um and one of them took me off for a fag...even though I didn't smoke (Ian).

The experience was more troubling for Ian in that he had a more personal relationship with the man. Both events were explained by the ward nurse as being natural and normal, that nobody had done anything wrong, the message being that 'stuff happens'. He reflects that at times in practice he has a 'gut feeling' and often unpredicted events happen that relate to premonitions about his patients. This resonates with the earlier reflective account, as a medical student, in which he observed the same 'skill' in another consultant.

Finally, as a house officer working in the Midlands during a very cold winter 'it was absolutely dire in that everybody died', it was a couple of years after qualifying in medicine, he was not being successful with his exams but 'wasn't enjoying it either so I switched to psychiatry'. The confirmation that this was the right career choice for him being clinical events where he perceives that physicians are dedicated to 'maintaining life at all costs', he perceives there is a reluctance amongst some consultants in admitting defeat and letting patients die:

Physician's won't say no, they just say go, go, go, go, go! (Ian).

This for him would not be a comfortable way to practice.

As a psychiatrist, suicide is his most urgent clinical dilemma made more problematic because of public perceptions, its high media profile and the need for apportioning blame. Much later in the interview he states:

I think if I've got a serious issue with death it's that the public perception of suicide is somebody's made a mistake or whereas it's actually part of the process of mental health. If somebody dies of a cardiac arrhythmia there's not resuscitation or coronary care because they've got ischaemic heart disease, you don't say, oh my God you've made a mistake, you say that's part of the natural history of heart disease and if somebody stops breathing because they've got terrible emphysema you don't say well why didn't you give them a lung transplant you know (Ian).

This statement appears to highlight the differences in practice and the public's perceptions between mental health and clinical medicine.

In response to my probing statement, 'it is an inevitable part of life isn't it to come into contact with death' he discloses a personal dichotomy:

Yes, I'm conscious that I've probably gotten very thick emotional protection against it in order to sort of protect other people but whether that protection, you know I put myself in the way of other peoples' actions. Whether that will work quite as well when it's me we'll have to wait and see. I suspect I'm a bit more vulnerable than I would like to think (Ian).

For Ian there is comfort with the familiar, the arena of his professional role, the personal aspects of death and dying being unknown and uncertain made him appear almost more exposed, less in control.

Mair has a more fatalistic approach to death and dying, mediated by her strong religious faith and belief that 'there are worse things than dying'. On reflection perhaps I should have probed this statement more as I am not sure what might be worse than dying, although I am aware this is a personal perspective. By way of justification, I think, she explained that her father died suddenly from a stroke and for him it was a good death, she reflected that it was appropriate in that he was at the right age, being elderly and until his death relatively well. Relating to her clinical experience her fathers' death was deemed 'good', in relation to the mode of death, in that it was not protracted or a dementia.

### **8.3.3 Conclusion**

The differences between Ian and Mair lay in their therapeutic approaches and *ways of being* in practice. It is these that appeared to characterise their experiences with Ian's certain, rather prescriptive approach being in contrast to Mair's more inclusive approach to patient management. Both made a clear distinction between their psychiatric speciality and clinical medicine.

Both were similar in their belief that dementia was a terminal condition from the time of diagnosis, that palliative care was helpful predominantly for those with a dual diagnosis and that end of life care was one of the least troubling aspects of the clinical role. There was little acknowledgement in their interviews of the holistic impact of a dementia diagnosis and the subsequent dementia journey; they almost appeared to distance themselves from the patient (and family) experience, this was characterised by their use of language.

The next part of the thesis seeks to locate the work within the wider context. It will focus the discussion with existing literature, related to clinical and patient perspectives in Chapter 9, theoretical perspectives in Chapter 10 and language and metaphor in Chapter 11.

## **PART 3: LOCATING THE THESIS IN THE WIDER CONTEXT**

### **CHAPTER 9 - DISCUSSION**

#### **STRUCTURAL CONTEXT: CLINICAL AND PATIENT PERSPECTIVES**

**Professional knowledge is constructed through experience and its nature depends on the cumulative acquisition, selection and interpretation of that experience. (Eraut 1994:20).**

#### **9.1 INTRODUCTION**

This chapter will locate the consultants' experience within the structural contexts of care, the clinical and patient perspectives which I initially thought would be central to the thesis. It concentrates on how consultants use technical clinical knowledge and skills in relation to considering referral to SPCS, however, this element turned out to be only part of their narratives and experience in caring for people at the end of life.

Other aspects of their experience were related to underpinning more theoretical concepts of the life-world, philosophical concepts of ways of knowing both personal (Polanyi 1974) and professional (Carper 1978; Dreyfus & Dreyfus 1980; Hunter 1991; Eraut 1994; White 1995; Chinn & Kramer 2008) judgement-based practice (Polkinghorne 2004) and clinical mindlines (Gabbay and leMay 2011) which will be discussed in Chapter 10.

#### **9.2 CLINICAL AND PROFESSIONAL DIMENSIONS OF EXPERIENCE**

##### **9.2.1 Contexts of care**

The shifting politics of palliative care seem to impact on the consultants' experience. At a strategic level there are attempts to develop and organise palliative care services to an agreed national template. Services should reflect the needs of cancer and non-cancer patient populations, be resource neutral and demonstrate cost effective fiscal and clinical outcomes. These requirements have impacted on the experiences of all participants who clearly articulated the tension between the management of their patient population as a whole and the care of the individual patient.



The participants reflected that the resource neutral requirement of extending palliative care to non-cancer patient populations was likely to compromise the care of all patient groups at the end of life as the resources available would be spread too thin (Addington-Hall et al 1998b; WHO 2011). Strategic and organisational directives have had implications at the micro level on the consultants' professional roles and responsibilities. The cardiologists allude to finite resources adversely impacting on patient care either directly or indirectly. The direct impact (on three of them) is evidenced by the fact that there are no specialist heart failure nurses in post within their socially and economically deprived geographical location. Indirectly they describe how the criterion for hospice admission has changed. It has become focussed on short stays to provide respite or to support active symptom management prior to the patient returning home or being referred for nursing or residential home care. Thus they believe many individuals with heart failure are now excluded from in-patient hospice care.

The evolution of specialist palliative care as a service for patients with more complex and challenging needs resonates with the experience of the cardiologists and old age psychiatrists whose stories reflect their own level of knowledge and skill being at a 'moderate' level, with most using palliative care as a resource and in validating their own practice. More infrequently, SPCS act in an advisory and consultancy capacity in supporting their management of especially difficult situations, predominantly those associated with a dual diagnosis. Mair, for example, referred a lady to palliative care who had mild dementia and a fungating head and neck cancer, it was the latter diagnosis which was beyond her scope of expertise.

Increasingly patients at the end of life have multiple conditions that would benefit from the care of several specialists. There is evidence, and a real risk that important aspects of their care may be neglected or missed as they are moved between specialists (Dixon. A blog Kings Fund 2011). It is thought possible that the consultancy or resource approach of SPCS might be a way of integrating specialist and generalist care to ensure patients' wider more

complex needs are met. This approach appears to be reflected in the stories of the cardiologists and old age psychiatrists.

All the consultants were aware that the knowledge and skills required to support the resource or consultancy approach would necessitate either further training of palliative care professionals or those from their own speciality. On further questioning, most supported the concept of reciprocal training whereby both clinical specialities up-skilled each other by a shared, peer learning approach. This approach is already being piloted as a peer-learning project between cardiology and palliative care (Cardiac Network, WG 2011).

At the strategic level there is the increasing acknowledgement that care at the end of life will be compromised by demographic changes, particularly an increasingly elderly population with multiple diagnoses and a reducing workforce. Strategies (WG 2009; DH 2009; 2011, WHO 2011) focus on increasing the skills of all practitioners in EoLC to ensure that specialist services are not overwhelmed and are used appropriately. This focus is consistent with their preferences for a more shared care approach articulated by the cardiologists and psychiatrists. Perhaps because neither of these groups have had the historical and rather symbiotic relationship with palliative care (as has been the case between oncology and palliative care) so this service model is more acceptable.

Palliative care somehow seems to have found a place as an established part in all the consultants' experience. Almost covertly there are elements in their narratives that suggest it is embodied and embedded in their practice albeit without their explicit acknowledgement. This is especially present in the cardiologists' stories where their active care incorporates a palliative approach in that they describe the need to not prolong futile interventions. The old age psychiatrists also almost routinely use the ICP in directing care.

For the oncologists their relationship with palliative care appears different. In describing their experiences the oncologists appear to be more accepting and inclusive of palliative care as fundamental to their everyday clinical practice.

They describe it as being an integral part of patient and cancer management; this perhaps equates with the historical development of palliative care which focussed on individuals with cancer (Payne et al 2008; Haines 2011). Their clinical preparation includes elements of palliative care as part of traditional oncology training. It may also relate to the perception of cancer as a life-threatening disease where at the point of diagnosis death is high on patients' agenda, with historically a cancer diagnosis being synonymous with death.

For the oncologists there is uncertainty as how the future relationship with palliative care will evolve. Greg states 'I feel there is a certain lack of clarity about just what patients they are prepared to take'. Most of the oncologists identified that palliative care appears uncertain as to its place in contemporary healthcare, that its role and purpose was less defined with political agendas requiring it to extend its role to individuals with a non-cancer diagnosis. This supports Ward et al's (2009) conclusions from their attitudinal survey of oncologists, highlighting their clinical dilemma as to whether they should collaborate or co-exist with SPCS. Strategic initiatives supporting greater inclusivity in palliative care provision concerned the oncologists as they feared a loss of resources for their patient group.

The tension between voluntary and statutory service provision, as described by Addicott & Hiley (2011), has contributed to disadvantages in service developments for both cancer and non-cancer patient groups. These are additionally compromised by the current economic recession. As predominantly described by the oncologists, many specialist palliative care services are charity led and only available in more affluent areas. This was a direct response to local fundraising which subsequently influenced the development and geographical location of services. For them, the historical siting of the local in-patient hospice was an example of a political decision not being thought through as it is on a different hospital site to that of the regional cancer centre making seamless service provision less likely. This reflects the national situation where most hospices are situated in middle-class areas, such institutions thrive on the benevolent middle classes from both a contributory and volunteering perspective (Hughes-Hallett 2010, 2011).

Clinical concerns in palliative care, as in other specialist areas such as mental health, are constantly evolving with some aspects of care being temporarily dominant, while others are displaced or marginalised (Pilgrim and Rogers 1999). Current clinical priorities in palliative care, identified by strategic directives, relate to preferred place of care, equity of access supported by new funding initiatives (DH 2011), shared decision-making and assisted dying. In-patient hospice developments and specific symptom management resources such as anaesthetic resources for managing complex pain syndromes are less dominant (WAG 2008, 2009). The consultants' experiences, irrespective of speciality, indicate that their clinical priorities relate to the direct care of individual patients such as providing resources to support more hospice beds, specialist professionals and pain services.

The consultants' stories all demonstrate an understanding of the need to function at all levels within the LHB; they demonstrate awareness of how the strategic, organisational and operational levels impact and are embedded in their practice. They articulate a tension between the conflicting priorities and perspectives between the macro, meso and micro levels of health care. These levels are inter-related and perhaps can be seen as a challenge to, and an enhancement of, their professional autonomy (Mohan 1996).

At operational and professional levels the increasing medicalisation of death has made skills, once integral in all medical practice the privileged domain of SPCS. Serving in part to deskill practitioners whose clinical experience, as described in this thesis, are at a high level and, for all three consultant groups are an accepted element of their speciality.

As seen in the interview narratives, for heart failure and dementia patient populations the uncertain disease trajectory and consequent difficulties in identifying the end of life make referral timings difficult and indicate that referral may not always be in their patients' best interests or even (as discussed earlier) required.

### **9.2.2 Clinical speciality and referral.**

Literature has highlighted a discrepancy between the need of heart failure patients for palliative care and their referral to SPCS (Gibbs et al 2006; O'Leary & Tiernan 2008; NCPC Minimum Data Sets 2009-10). Consistent with data from O'Leary et al's (2009) comparative study, the cardiologists experience in practice seems to reflect that for most people with heart failure their palliative care needs can be met within the existing cardiology services, that their palliative care needs have been over-estimated. Most patients valued highly the close monitoring, symptom and medication management, ease of access and familiarity with those involved in their care within existing services (O'Leary et al 2009). The valuable elements of the cardiology service, reported by the patients in her study, were almost identical to the cardiologists' experiences and their proxy estimation of what was important to their patient group, the only omissions being the provision of a telephone support and outreach service (although during the interviews the cardiologists recognised this as being a gap in their service).

Specifically in relation to this thesis O'Leary's study identified potential tipping points in the patients' journey where the focus should change from active treatment to palliation: deterioration despite optimum therapeutic support, increasing fatigue, increasing functional dependence, low ejection fraction, recurrent hospitalisation, emotional distress, carer fatigue and patient request. Thus there is a clear combination of holistic factors that should precipitate referral (O'Leary et al 2009). The cardiologist's stories demonstrated recognition of most of these factors as providing evidence of imminent dying but appeared uncertain as to whether they were reversible causes or evidence of permanent deterioration, these linked with their perceived difficulties in prognostication and diagnosing dying.

Health care organisations have adopted an increasingly evidence and outcome based approach to professional practice and these, according to Polkinghorne (2004) and Gabbay & leMay (2011), appear to lessen the individualised approach to care. For example, specific techniques, procedures and programmes are evident in relation to all the clinical

specialities explored in this thesis. In cardiology, especially heart failure, the use of specific medical and device therapy appear to have prolonged life, for example cardioversion (British Cardiovascular Society 2006; NICE 2010). In oncology the use of combined rather than single agents in administering cytotoxic chemotherapy has led to improved therapeutic response and lessened side-effects (Tadman & Roberts 2007; NICE 2011a). In old age psychiatry the use of new drugs such as Aricept and Ebixa has delayed the progression of dementia for a small number of carefully selected individuals (National Council for Palliative Care & the Alzheimer's Society 2006e; NICE 2011b)). In palliative care the use of combination chemotherapy or subcutaneous syringe drivers in managing patient's symptoms in the last days of life and the integrated care pathway for the last days of life have made for improved patient and care experience (Dickman et al 2005; Chan & Webster 2011). All the preceding interventions are supported by evidence based guidelines but also imply increasing medicalisation at the end of life. It would be inappropriate to negate the value of these approaches but they may increase uncertainty in relation to active versus palliative interventions.

For Polkinghorne (2004) everyday caring practice requires something qualitatively different from the application of technique, rules and standardised behaviours. There were a number of participants (not the oncologists), who supported the use of the integrated care pathway for the end of life as facilitating end of life care. However, all contextualised this with acknowledgement of the caring elements, that the use of clinical judgement and knowing was intrinsic to the use of the pathway and that it relies on accurate prognostication in determining the last days of life which (which will be discussed later in this chapter) is clinically and technically problematic.

The cardiologists' professional role as described in their interviews provides evidence of their extensive array of clinical skills and the clarity with which they were able to elucidate the complexity of their clinical care. Their care, being scientifically associated with medical and device therapy, focuses on the causes of heart failure rather than the symptoms and has a large number of therapeutic options (Ellershaw & Ward 2003). The issues, as supported by

Gott et al 2007, Goodlin 2009, Hupcey et al 2009, related to palliative care referral are inextricably linked with prognostication difficulties associated with the uncertain disease trajectory of heart failure and patients' negative perceptions of palliative care. These will be discussed later in this chapter.

As supported by the NCPC (2006a) the oncologists' referral to palliative care is more routinised and commonplace, most referrals relate to proactive planning of care that may improve quality of life for both patients and family members. For all, the use of and referral to palliative care is regarded as best practice. Despite this positive approach to involving palliative care services in the care of their patients they describe, from their experience, some negative perceptions of palliative care. For the oncologists, palliative care appears to resonate with Murray et al's (2005) view that it is a place of care, supports a more peaceful death, provides appropriate medication and a holistic approach to care provided by experts, that is the essence of palliative care.

The oncologists' perceptions of palliative care relate to concerns of where it fits in the context of cancer care. Hermione is very clear that palliative care makes her life easier, that it facilitates a better death or acts as a safety net for patients receiving more active interventions for cancer. She reflects that perhaps she refers her patients too early but the focus of her approach is to achieve a collaborative relationship between oncology and palliative care rather than seeing palliative care as a threat. Many of the oncologists believe that patients and families view palliative care negatively, that the word "hospice" is associated with cancer and implies that the individual is going to die and that hospice admission is a 'one way ticket' (Ahmed et al 2004). They believe these perceptions are changing albeit very slowly.

Two of the oncologists suggest that palliative care has lost its way, and become more acutely interventionist in that it no longer provides the environment that supports a peaceful death. From their experience it appears that many hospices are uncertain as to their place in end of life care; most perceive themselves as being more active support units rather than as a place to die. This tension was recognised and described earlier by Byock

(1998) as being a 'tug of war' between loyalists and progressives. The loyalists remain true to the early ideals of the hospice movement, that it was a centre of excellence and a place for 'best' care at the very end of life whereas the progressives are encouraging a more inclusive approach with the extension of palliative care services to other health care settings and diagnostic groups. It is clear from global and national agendas that the progressives have prevailed, perhaps in response to changing demographics and economic constraints (WG 2010; DH 2011a; Hughes-Hallett 2011; WHO 2011).

However despite the strategic direction being well articulated and resourced the debate as to the role of palliative care still continues in the virtual environment of professional and patient websites. The names of the websites convey the emotive elements associated with care at the end of life:

[www.dyingmatters.org.uk](http://www.dyingmatters.org.uk);  
[www.carenotkilling.org.uk](http://www.carenotkilling.org.uk);  
[www.iwantgreatcare.org.uk](http://www.iwantgreatcare.org.uk)

All have been inaugurated by professionals actively involved in palliative care service provision and spiritual groups. For most people, dying at home would be their preference but if not possible a hospice would be their favoured alternative (BBC 2006; Marie Curie Cancer Care 2007).

Overall, the oncologists appear more comfortable (than the cardiologists and old age psychiatrists) in their relationship with palliative care, suggesting that this may relate to closer working relationships being established throughout the illness course, that cancer has a more predictable disease progression and that prognostication and diagnosing dying is less complex (Lynn & Adamson 2003; Murray et al 2005). This supports evidence from the Gold Standards Framework position paper on prognostication at the end of life (GSF 2006). Two of the oncologists were nearing retirement; their narrative experience, biography and ways of knowing had clearly been influenced by the evolution of palliative care during the 30 or more years that they had been practising as oncologists.



For the old age psychiatrists, dying from progressive dementia appeared not to be a clinical dilemma or a particular personal concern. These were described by Benbow & Jolley (1997) as unavoidable stressors that were anticipated as part of routine practice, whereas death by suicide was more of a personal and professional dilemma associated with unpredictability, powerlessness and a perceived wider societal impact. The recent literature accessed does not seem to support this viewpoint, most reflects the negative experiences of people dying from dementia and does not identify with the consultants' perspectives of end of life care in dementia presented in this thesis. McCarthy et al (1997) provide evidence that people dying from dementia in the last year of life need more help and support than those dying from cancer. Recent government initiatives, based on audit and research data, conclude that for those with dementia end of life care services are not appropriate in meeting their needs (NCPC 2009a; Alzheimer's Disease Society 2010; National End of Life Care Intelligence Network 2010; WG 2010; DH 2011a). In this thesis, the old age psychiatrists position may have been influenced by the fact that they were less 'hands on' in the care of their dementia patients at the end of life, most were cared for in nursing and residential homes outside the hospital environment and beyond their clinical jurisdiction and daily practice.

All the consultants made reference to always being able to offer something from their clinical skill set that would ameliorate patient distress. However, it was unclear whether these interventions were active, palliative or placebo in intent; they linked the interventions with their need to maintain an optimistic approach and being a response to patient and family expectations. For the cardiologists this was usually related to physiological, pharmacological and device therapies, for the oncologists it linked to active treatment modalities linked to disease progression, such as radiotherapy for bone pain or biphosphonates to treat hypercalcaemia. The old age psychiatrists described interventions to treat reversible causes of patients decline, such as infections. All these therapeutic options appear to have a palliative intent in that their aim is to promote comfort rather than to treat the underlying condition. From their narratives it was clear that there was often a patient or family expectation that

something could or should be done which impacted on their decisions in practice.

### **9.2.3 Trajectories and prognostication**

Macro and meso-level end of life care policy documents and guidelines suggest that referral to SPCS should be based on the establishing of an end of life prognosis (DH 2008; WG 2010; WHO 2011; Addicott & Hiley 2011; Gott et al 2011). Reflecting on much of the evidence found in the literature at the micro-level, for the individual patient unpredictable disease trajectories make prognostication and the identification of a 'tipping point', a downward trend towards the end of life problematic (Teno et al 2001; Lunney et al 2003; Murray et al 2005; Dy & Lynn 2007; Gott et al 2011). This is reflected in the experiences of all the consultants in this thesis.

Trajectory, as described in the literature review, refers both to an individuals' illness journey but also identifies the required role of professionals in their care at various stages of their illness (Strauss et al 1997). Initially it was a term developed in the context of hospital-based care illustrated by Strauss and his colleagues in *The social organisation of medical work*. The appropriateness of the concept of trajectories for discussion of life threatening illness and transitions to end of life care is evident as it focuses on the experience of patients and their needs for care. Unfortunately, in end of life care this focus on illness appears rather medicalised and reductionist.

It is important to acknowledge Strauss' involvement in an earlier influential piece of work *Awareness of dying*, which although not directly relevant to this thesis has greatly influenced medical practice at the end of life (Glaser & Strauss 1965, 2005). They developed a theory of dying awareness (closed awareness, suspicion awareness, mutual pretence, and open awareness) from observation of the social interaction of the dying and those around them in the American hospital setting. They raised professional awareness and understanding of the importance of who knows what about dying and what difference it makes. As a direct consequence of their work (and that of subsequent authors) more honest and open dialogue in communicating

diagnosis and prognosis has been inculcated into best practice at the end of life in confronting the many ethical and practical (personal) dilemmas that arise at the time of dying. It is possible that Glaser & Strauss' evidence (1965) may have acted as a catalyst for the development of palliative care when considering the chronology of events in relation to the evolution of palliative care (Payne et al 2008).

Without Glaser & Strauss' work this thesis would have been more difficult as it is based on the assumption that all the consultants communicated openly with their patients. They all described open communication with their patients, the specific difficulties they experienced in communicating uncertainty and establishing an end of life prognosis were reflected by Glaser & Strauss' observations from the patients' perspective and reconfigured by Christakis' exploration of prognosis from the physicians' perspective (Glaser & Strauss 1965; Christakis 1999).

Recently the Gold Standards Framework (DH 2006; 2008), from strategic and organisational perspectives, have linked the concept of trajectories to the need for diagnosing dying. As a consequence, because of the uncertainties intrinsic in many disease trajectories, access to SPCS is either helped or hindered (Murray et al 2005; Dy & Lynn 2007). This reflects Strauss et al's earlier conclusion that trajectories can be reasonably straightforward or reasonably challenging and a change in the patients' illness has an impact at the macro, meso and micro levels of health care (Strauss et al 1997).

The cardiologists' stories seem to reflect the 'roller coaster' nature of the heart failure journey. Their experiences reflect incidents of preparing the patient and or families for imminent death only for the patient to rally and recover. Other experiences reflect on sudden, unpredicted events which act as an extra insult 'that tips patients over the top very quickly' and death occurs. This is consistent with evidence which supports deaths from heart failure occurring either as a result of a slow, progressive and undulating generally physical decline or a sudden acute event (Finucane 1999; RCP 2007).

By contrast the oncologists' description of the cancer journey suggests a gentler, predictable illness course with palliative care being appropriate at many stages of the journey. Palliative care is deemed useful in managing the complex symptoms and side effects associated with active cancer treatments such as cytotoxic chemotherapy or in supporting patients or family members in adjusting to a cancer diagnosis or at the time of transition from active to palliative care. This is consistent with and reflected in Picardie (1998) and Diamond's (1999) personal narratives of living with progressive cancer and the more public online cancer journey of Jade Goody and Steve Jobs (Facebook 2009, 2011). All these narratives acknowledge the benefits of palliative care but also describe the intensely personal and complex nature of the journey towards death.

The old age psychiatrists appear to describe two sorts of dying for people with dementia, the social death (which appears to relate to loss of mental faculties and the ability to interact socially) and the death of the body, (the physical death). For them palliative care referral appears only appropriate for the management of physical symptoms (such as pain) or conditions related to bodily deterioration (such as pressure sores or wounds). This is in conflict with palliative care's holistic philosophy that has, since its inception, characterised approaches to care (Kubler-Ross 1969; Saunders 1976; WHO 2011).

Muller & Koenig (cited by Lupton 2003), from ethical and sociological perspectives, emphasised the social nature of defining death by exploring the processes by which doctors interpret selected information about patients to reach conclusions about whether the patient is 'dying' or 'still has a chance', The consequence being whether instigating further medical intervention designed at averting death is appropriate. Many of the consultants described situations in the dying trajectory which were reversed by therapeutic interventions such as antibiotic therapy, appearing clear that these interventions were related to promoting comfort rather than as an attempt to prolong life at all costs. This supports the notion that the treatment of illness still relies upon interpretation of the patients' situation as well as the

possession of the appropriate knowledge and the perceived benefits and burdens of the proposed interventions (Montgomery 2006).

Mair and Ian describe dementia as a terminal illness, a terminal condition at diagnosis, this is consistent with the patient stories revealed in *Out of the shadows: End of life care for people with dementia* (NCPC 2009a). It is not an acute condition and end of life for this patient group is a long process compared to other terminal illnesses. From their experience they describe the pattern of dying with advanced dementia as being similar to that of heart failure. The difference being that the decline is progressive, generally unremitting and is characterised initially by a mental and cognitive decline whilst the individual remains physically robust; this is subsequently followed by a physical decline manifest by increasing frailty and immobility. For some individuals with advanced dementia death may also be precipitated by an acute event, characteristically a chest infection or myocardial infarction. Their stories are consistent with Mitchell et al's (2009) medical description of the clinical course of dementia and the patient and carer perspective presented by the NCPC (2009a).

The cardiologists' response to prognostic uncertainty seems to be characterised by a largely optimistic approach to their patients' care. Most believe that referral to palliative care, or acknowledgement of a terminal decline, may have a detrimental psychological effect on their patient group. They describe life with heart failure for patients and families in their care as being characterised by uncertainty and many false alarms. Dan describes his experience of the complexities and dilemmas clearly, in that once heart failure gets beyond a certain point patients are at high risk of death from arrhythmia which is, in terms of mode of death, very quick. Alternatively he describes the problem where progressive decline is accelerated by either multiple organ failure (especially troubling is renal failure) or any concomitant illness such as diarrhoeal illness which leads to death as 'there's no reserve so they tip right over into renal failure and it is not a nice way to die but it is hard to predict the actual death of anyone'.

In their practice, the cardiologists appeared to offer an approach to care that, at first look, appeared to be death denying in that their technical and interventionist approaches pervaded their stories and experiences. Looking deeper their care seemed to, without awareness, be offering a sort of palliative approach that all were aware that heart failure was a life-threatening condition, that aspects of care were multifaceted. Their focus was on well-being with a palliative care referral being seen as deleterious, both physically and emotionally. It was clearly part of the consultants' experience that the avoidance of or the duty to share a prognosis, albeit implicitly suggested for them that a palliative care referral can be either helpful or harmful. Their approach is supported by two experimental studies of individual physicians' beliefs about the self-fulfilling prophecy providing confirmation of the adage that 'no news is good news', that saying nothing, not establishing a prognosis has a beneficent rather than a maleficent effect and that optimistic predictions cannot harm patients (Christakis & Iwashyna 1998; Iwashyna & Christakis 1998).

Described in Iwashyna & Christakis' (1998) national study of medical internists there was also an acknowledgement in many of the consultants' stories of the belief that patients' outcomes can be affected by a kind of 'self-fulfilling prophecy'. For most, these outcomes were likely to be negative as in Alex's story, where he is reluctant to discuss palliative care explaining the difficulty in terms of continuing active interventions, supports a more 'optimistic' outlook, whereas referral to palliative care is a more 'depressive outcome' and may precipitate a terminal decline and have possible deleterious effects both physical and psychological on the patient by adopting a pessimistic approach to their situation. His story was the most certain that predictions of the future can influence people to behave in ways that make those predictions come true; from the patients perspective a change in attitude or behaviour may promote the predicted outcome. Christakis (1999) further develops the idea of prognosis being akin to prophecy, its resemblance linked to the structural, functional and symbolic elements of prognostication. Thus in medical practice it is more than a technical activity as it is imbued with meaning and demands creativity on the part of the physician.

The influence of prediction, described by Christakis (1999), draws on earlier anthropological work suggesting the idea that 'voodoo kills'; that by making someone aware that death is near may hasten their death. This was not explicit in Alex's interview but throughout there was an element of caution, almost reluctance related to referral to palliative care that was not just related to clinical and prognostication dilemmas. This caution is supported by the earlier concept of 'voodoo death', the 'nocebo' effect whereby the causation of sickness or death is influenced by the expectation of the same. This was first described by Cannon (1942) an anthropologist as 'the fatal power of imagination' more recently it has been discussed as the problem of death by suggestion (Lester 1972; Lewis 1987). This links with the idea present in some interviews of the negative risks of making predictions.

This relates closely to my early experience as a young staff nurse when a young mother was told her leukaemia was not responding to treatment and she would as a consequence die very soon. I watched, as over the next few days she refused to see her family, refused to eat and drink and actually (not metaphorically) rolled over and turned her face to the wall. She died within five days, the consultant had predicted to the medical team and her family that she would survive for a few months and was convinced that she had 'willed herself to die'.

Alex, together with the other cardiologists and both old age psychiatrists, also recognised that a negative prediction can change the doctor's attitudes and behaviour in the way that the predicted change is promoted. This is exemplified by the giving of a prognosis occurring in tandem with the establishing of a DNAR order.

The consultants reflected that most clinical experiences were characterised by a trusting relationship with their patients, thus because patients trust the doctor an unfavourable prediction is likely to have an unfavourable impact (Lamont & Christakis 2001, 2002, 2003). This is especially relevant in end of life care, most of the predictions made are unfavourable in relation to the patients' journey ultimately ending in death. Montgomery (2006), drawing on

her earlier ethnographic observations, indicates that there is reluctance for doctors who have had long relationships with their patients to disclose a changing focus for care from cure to comfort. They appear not to want to harm the patient or the relationship between them, this reluctance is also present in Atkinson's study of American haematologists (Atkinson 1995) and in Lupton's discourse on *Power Relations and the Medical Encounter* (Lupton 2003).

The oncologists' experiences were different in that for them giving a poor prognosis may have more positive consequences by enabling the patient to make plans and maintain a positive focus which as Hermione describes is 'hard work'. It may also avoid potentially unfavourable outcomes such as being 'treated to death'. Frank conversations about limited life expectancy were an essential and routine part of cancer care, this may relate to historical perceptions of a cancer diagnosis being akin to a 'death sentence' (Field & Copp 1999; Hinton 1999).

For the oncologists palliative care was nothing special, it was integral part of care and an intrinsic element of the patients' journey, this is supported by the recommendations of Haines (2011). Clinical foresight enabled the patients to be pre-educated or prepared for referral, thus it is part of usual care and not an unexpected experience. The oncologists describe times when their patients appear to have had enough and readily accept palliative care referral. For a small number of patients palliative care referral can be read the wrong way, it is either something they have never heard of or confirms the belief that they are going to die, Flynn highlights his role as being to correct these misperceptions.

The oncologists' stories seemed to describe more of a partnership approach in their relationships and communication with their patients. This may relate to the high profile 'voice' of many cancer patients and is characterised by the experiences described by the anthropologist Susan DiGiacomo (1992) who attempted to up-skill her knowledge of her cancer, treatment and outcomes as a way of enabling a more equal and participative relationship with her



oncologists. This was described by Lupton (2003) as being problematic in making DiGiacomo aware and share in her doctor's worries and their difficulty in dealing with therapeutic uncertainty especially in relation to establishing a prognosis.

Christakis (1999) explains that the making of a prognosis by implication changes the perception of the future for both patients and doctors. The structural purpose of prognostication, as suggested in this thesis, might support or deny access to specialist services, this is supported by the recommendations *the Prognostic Indicator Guidance Paper* (GSF 2006) that referral and the establishing of an end of life prognosis are inextricably linked.

The old age psychiatrists' link prognostication to the use of the integrated care pathway for the last days of life, in considering the mental deterioration associated with dementia there was understandably no explicit mention of how making a prognosis impacted on their patients, the consequences were related to family members. In practice however, the consultants' experiences suggest that talking about palliative care referral is more usually used as a signal that the patients' situation is deteriorating. The rather ambiguous phrases, such as changing gear or altering the direction of travel as described by the cardiologists or the safety net present in the oncologists' narratives, characterise their approaches to discussing palliative care referral (this is discussed more fully in Chapter 11).

None of the three groups were explicit in sharing or establishing a specific life expectancy but they valued the opportunity of talking about uncertainty as a way of supporting patients and or families to 'put things in order'. Research indicates that cancer patient preferences in relation to information giving regarding prognosis varies in relation to the level of detail provided and their consequent understanding (Hancock et al 2007; Innes & Payne 2009; Stevinson et al 2010). For the oncologists, prognostication was thought to be easier both from a more physiological and disease patterning perspective. It was also made easier by the public perception of a cancer diagnosis being synonymous with death.

Goodlin & Cassell (2008) recommend that patients and families should be warned at the time of diagnosis that in heart failure, death may occur suddenly or may be as a result of gradual deterioration. This practice was supported in all the cardiologists' interviews as they described communicating at the outset that heart failure is a terminal diagnosis. They suggested that this information is diluted by the trajectory of heart failure and public perceptions which are polarised. Some patients fear a sudden, unexpected death whereas others believe technological advances such as pacemakers and 'plastic' hearts make death unlikely; many choose to believe heart failure is a life-limiting rather than life-threatening diagnosis (Goodlin et al 2004; Selman et al 2007; Goodlin 2009). O'Leary suggests that this belief may have indirect impact on the cardiologists' approaches to end of life care and this resonates with the cardiologists' described experiences (O'Leary et al 2009).

Again the old age psychiatrists describe dementia as a terminal condition but unlike cancer and heart failure the journey from diagnosis to death is lengthy and protracted with death perhaps coming as a 'relief' to all concerned (NCPC 2009a; WG 2011).

Not found in the contemporary literature were the reflections made by all the oncologists during the interviews, that prognostication was different and difficult for different types of cancers. Prognostication is easier for those with, for example, a diagnosis of lung cancer rather than those with ovarian cancer and brain tumours. They, consistent with the existing literature, recognise the difficulties of prognostication for conditions other than cancer, specifically heart failure, chronic obstructive pulmonary disease and neurological conditions. The oncologists all made contemporary reference to the difficulties inherent in prognostication by citing the case of the Lockerbie bomber, Abdelbaset Ali al-Megrahi, who was released from a Scottish jail and returned home to Libya on compassionate grounds in August 2009. The rationale for release being that he had only a few months to live due to disseminated terminal prostate cancer. He has recently (December 2011) given his 'final' press conference, but at the time of writing remains alive.

There is some evidence in the literature, which did not appear to be present in the consultants' stories, that the establishing of a prognosis is a manifestation of medical power and dominance, which as consequence requires certain behaviour from the patient or the family. Medical consultants appear to have power because of the professional dominance and clinical autonomy associated with their specialist knowledge (Friedson 1970; Lupton 2003; Willis cited in Lupton 2003). The consultants interviewed for this thesis appeared in their stories to be very tentative and were aware of the symbolic consequences of making a prognosis. Many were aware of the negative consequences of establishing an end of life prognosis, especially if it were premature and the person recovered – this was present particularly in the experience of the cardiologists and old age psychiatrists with the uncertain trajectory associated with heart failure and dementia. Kleinmann (1988) and Montgomery (2006) are clear that this unpredictability, and the meanings attached to their illness by patients, requires the consultants to be understanding and have the skills of dealing with uncertainty and managing the limitations of modern medicine rather than exercising medical power.

#### **9.2.4 Patient perspectives**

The consultants' experiences reflect the dilemmas for patients and families in perceptions of, and access to, end of life care provision. Patients' personal and family contingencies had a major part to play in complicating or encouraging access to SPCS.

Geographical location was consistently mentioned in the participants' stories: rurality is described as a problem, impacting on access to services and their sustainability, rural services are generally less robust (House of Commons Health Committee 2004). The oncologists and cardiologists identified that more isolated communities were disadvantaged both in having to travel for specialist care and receiving less support in the community. Cancer services in particular were described as being very 'city-centric'. The model of service provision in South Wales relies on the specialist services being based in regional cancer and cardiac centres based within acute hospitals which have historically been developed in areas of population density.

Old age psychiatry services appear less centrally located; both Mair and Ian described services as being available in local hospitals situated within urban and rural communities. The changing provision of mental health services was minimally apparent in their stories, the only acknowledgement being that more long-term care was provided by the nursing and residential home sector.

Most of the consultants reflected that because many specialist palliative care services (both community and in-patient), are predominantly charity led, they are only available in more affluent areas this being a direct response to local fundraising and political influences which influence the development and geographical location of services (NCPC 2007, 2010; Addicott & Hiley 2011; Hughes-Hallett et al 2011). This led to many patients, often the most needy, being disadvantaged especially those living in more rural or isolated communities, they are less likely to receive SPC. The oncologists were all linked to a city-based regional oncology service and acknowledged that many of their patients were compromised by having to travel long distances to receive certain therapeutic interventions such as radiotherapy.

Ben was the only participant to directly compare the provision of specialist cardiac services at national level, having worked in central London before returning 'home' to Wales. He described the provision of services in Wales as being poor, with no specialist heart failure nurses to support patients at the time of diagnosis or throughout their disease journey and no time to focus on the more holistic elements of patient care. Uniquely, Ben is a specialist working at a tertiary centre who refers patients back to their local services when their condition is no longer responsive to active interventions. He provided a specific example of service delivery at the time of diagnosis as an ideal, the 'gold standard'. This service offered patients at diagnosis a lengthy appointment in which the medical consultant communicated the diagnosis and outlined the medical therapeutic options, this was followed by an appointment with a nurse specialist who supported the patient and family by providing information, counselling, guidance on self management strategies and exploration of the more holistic aspects of care. It was a model of service delivery described and preferred by his cardiology colleagues, most

acknowledged that due to a smaller potential patient population and resource constraints this may only be workable as a regional service.

Ben was the only cardiologist who explicitly identified the different family structures *[which]* support or deny care, with families being present or absent in the patients journey. In Wales he believes the average family has an immense amount of support with large extended families where even if there are not direct relatives there are usually plenty of people willing to be involved in somebody's care. When encouraged to make comparisons with his London experience he describes a situation where patients are pretty much on their own and there are huge variations in what is available. Some patients, who have nobody to look after them, are entirely dependent on hospital services until they die. This he describes as being a rare experience for his Welsh patients.

The other participants made no overt comments implicitly acknowledging the family as part of the unit of care and that this was the norm. The oncologists mention particular family situations in which referral to specialist palliative care is actively encouraged, for example the support of patients with young children, husbands not coping with a wife's diagnosis or families who are likely to 'panic'. For the cardiologists referral is deemed more appropriate for articulate, communicating and coping families. For most of the cardiologists it is family members who request referral or are actively involved in the referral decision but requests for referral are very rare (O'Leary et al 2009).

Reflective examples in the oncologists' stories identified patients who are disadvantaged in accessing SPC services: being those who live alone, have a dysfunctional family, mental health issues or are very old or very young. Family members were acknowledged in all of the stories as encouraging or discouraging referral. This picture is consistent with historical evidence from global and national population studies (Gray & Forster 1997; DH 2000a; 2001; Koffman et al 2001b; WHO 2004a, 2004b; NICE 2004; Ahmed et al 2004; WHO 2008).

Only the oncologists specifically mentioned patient age as influencing referral. Younger patients with dependent families and those of an older age were more likely to be referred. Burt & Raine's (2006) systematic review reported quantifiable differences in that younger cancer patients were more likely to be referred to or use SPC services. In the discussion section they state that the studies used in the review were characterised by methodological weaknesses and a failure to consider difference in use in relation to identified need, for example are younger patients more likely to manifest greater distress. This is consistent with Flynn and Hermione's description of critical incidents in which younger cancer patients present with greater physical, psychological and social distress which acted as powerful motivators for referral. Referral being seen as a way of providing extra support, the safety net, described earlier in Chapter 7. Anecdotal reports suggest that specialist palliative care, irrespective of diagnosis, is more likely to be offered to those patients who are either the same age or younger than the clinicians caring for them.

The oncologists described their personal experiences, for many families' palliative care was synonymous with death and this acted as a big block that led them to be reluctant or distressed when referral was suggested. This may relate to the historical development of palliative care being for those generally dying from advanced cancer and therefore reinforced peoples' fears about referral. Greg does rather mischievously reflect on a number of families who requested a hospice admission for their mother or father to enable them to go on holiday, there is no evidence found in the literature to support or refute this opinion.

The experience of family involvement in dementia care was less commonly discussed by the psychiatrists. Mair describes their need for respite and information about disease progression whereas Ian describes his role in managing complaints and in dealing with family members' unrealistic demands. Family involvement in decision making regarding DNAR orders, which in the literature is regarded as problematic, is described by them in a very pragmatic way. The experiences of end of life care appearing very

'ordinary' and not very problematic, however it is not possible to generalise from the experiences of the two psychiatrists.

### **9.2.5 Physician perspectives**

Atkinson's (1995) ethnographic study of American haematologists contains elements which are specifically relevant to my thesis. In particular the sociological and anthropological consideration of the relationship between medical knowledge, medical language and the increasing technological context of medical practice (which in end of life care is characterised by the concept of the medicalisation of dying).

Unlike this thesis, Atkinson observed the doctors in practice whereas my approach was to explore their experiences in practice indirectly as part of a reflective interview. In this thesis the patients' experience of illness is elicited by concentrating on the medical consultants' descriptions of their patients' situation and by helping them in attempting to understand their professional responses.

Their clinical experience is constructed by the interview narratives which have been analysed descriptively, interpretively and linguistically earlier in this chapter and positioned within the nature of clinical practice in contemporary society. This involves consideration of theories of decision making and clinical judgement which are supported by ways of knowing. The physicians' experience and judgement integrates the themes of ways of knowing derived from medical and nursing literature (Carper 1978; Benner 1984; Chinn & Kramer 2008). It is informed and located in the particular complex care arena of end of life and relates to their clinical speciality.

The participants remembered and described experiences that were their most memorable (rather than the most common) and those events that required more attention. Their experiences were mediated by preconceptions shaped by their earlier experiences, other people's attitudes and the professional medical culture. Their voices articulated the recurrent uncertainty in clinical practice and patient care, the conflict between experience and empirics.

The nature of health care in the 21st-century was also a universal factor impacting on the consultants' role. As discussed earlier, its increasing attention to outcome measures, the use of clinical guidelines and increasing litigation appear in their stories to have negated elements of clinical freedom and clinical intuition. Aspects of death and dying and care for people at the end of life was a shared experience for the participants. They reflected the general reluctance to talk about death and dying present in Western society, together with concerns as to the increasing medicalisation of healthcare and dying.

It is likely that the role of the medical consultant is still viewed as having status that imbues the individual with power and authority. This view is held both by patients and other members of the multi-professional healthcare team (Hunter 1991; Atkinson 1995; Lupton 1997, 2003). Gott et al's recent focus group study (2011) reflects the dominance of medical consultants and professional hierarchies as impacting on the ability of junior staff to input into decision making at the end of life. The hospital setting provided an additional barrier to transitions from active to palliative care.

All the consultants described and share an acknowledged high status position within the medical hierarchy. Their different specialist areas of practice they perceived as having a different value, for example the cardiologists (as described earlier) perceived their practice as being of higher status than that of palliative care specialists. All, consistent with the literature, provided evidence that establishing and communicating an end of life prognosis was their sole clinical responsibility (Schofield et al 2006; GMC 2010; Gott et al 2011).

The consultants' stories all acknowledge the importance of particular personal experiences in influencing their practice, together with a range of other diverse experiences. The contribution of these experiences enabled the consultants to understand the values and assumptions impacting on and underpinning their practice and how their practice might be improved by heightened



awareness and understanding. This may draw a parallel with the concept of reflection in helping individuals to deepen their practice (Schon 1991).

The death of a close family member was not a universal experience for the cardiologists, only Chris had personal and direct involvement. Describing the death of his mother from a brain tumour, he reflects that although dying from cancer is different to that of heart failure, this experience informs the care of his patients at the end of life. He describes his decisions to involve palliative care as being evolutionary, informed by the personal perspective of the 'grandmother or father test' that being whether he would want referral if he were a family member. He believed that palliative care accelerated and managed, albeit appropriately, his mother's demise, that her dying was not prolonged. This has given him the sense that death can be managed. Individually it has made him death denying, wanting to die as late as possible at an advanced age.

Dan discussed a proxy experience of death and dying as part of his initial training, he was encouraged to hear patients' stories related to their death and dying as being good preparation for care of the dying. Personally his fears of death relate to the mode of death, the dying process rather than the death itself, he believes that this is also the key issue for patients and families.

Three of the oncologists described personal experiences. Two, Eve and Hermione, acknowledge that these have positively impacted on their professional role. Hermione in particular describes her grandfather's death over ten years ago as being always very present, embodied deep within her influencing her professional role, she is always open and honest with dying patients giving them options, being aware that good care is compromised by a bad death or experience. Eve reflects that the death of both her patients has impacted in two ways. Firstly on her awareness of the difficulties of caring for people dying in their own homes and secondly on the importance of not using personal experience as a way of influencing family behaviours or decisions. She describes her unique experience of being an orphan as making her more reflective and measured in practice.

Greg disagrees negating the influence of parental death by being very clear that he had already become his own person before they died. Their deaths were sad but timely and not unduly distressing, although he had left home before they died and suggests this may have lessened the impact.

On reflection I wonder whether there is a gender difference in the personal experience of death, loss and grief. The literature is equivocal in relation to gender and loss, perhaps influenced by most historical research focussing on couple bereavement and the perspective of widows (Field et al 1997). Listers' review of male grief (cited in Walter 1994) focuses on the positive aspects of grieving relating to them being able to resume normal life and functioning as soon as possible.

All the participants' experiences appear to demonstrate discrete differences between clinical understanding and clinical knowledge, this is characterised by the distinctions they make in their narratives between the treatment of disease and the care of an individual with a particular illness. Both require a combination of technological, existential and human skills. This has been described by Fish (1998) as 'professional artistry' which is concerned with skills but also the invisible aspects of practice such as capacities, abilities, assumptions, theories, beliefs, values and the moral dimensions including practitioners professional judgements. The consultants' stories appeared to illustrate the dilemma of just because you *can* do something it does not necessarily mean you *should* do it. The old age psychiatrists and cardiologists described the dilemma of DNAR decision-making and withholding and withdrawing of interventions for example antibiotics, the oncologists describing the requests for futile treatments such as experimental cytotoxic chemotherapy.

The consultants all share a common profession but it is clear from the interviews that each group has a unique culture and has developed their own working practices which impact on their patient management, their perceptions of palliative care and subsequent referral practices. The factors derived from the literature review as potentially impacting on referral to SPCS

do not appear to fully resonate with the narrative experiences articulated by the consultants in this study. It may be that the specialists' immersion in their own area of practice was implicit in their responses and as a consequence presented their unique perspective.

#### **9.2.6 Conclusion**

The first part of the discussion section has presented a dialogue between the experience of my participants and the existing clinical and professional literature - the structural context. Reflecting the content of the consultants interviews the discussion focussed on trying to understand how the contexts of care, their clinical speciality and difficulties associated with disease trajectories and prognostication together with patient and physician perspectives impacted on their decision-making. The purpose of this chapter was to establish links with existing clinical literature before deepening the discussion and locating it within wider theoretical frameworks in the next chapter.

## **CHAPTER 10 - DISCUSSION**

### **THEORETICAL CONTEXT: CLINICAL THINKING AND KNOWLEDGE IN PRACTICE**

**Despite medicine's miracles, and they are legion,  
clinical knowing is not certain nor will it ever be.  
(Montgomery 2006:38)**

#### **10.1 INTRODUCTION**

The aim of this chapter, and my task within it, is to bring out the more theoretical dimensions of the consultants' experience and show the structural whole that is socially shared while also experienced in individual and particular ways. It will attempt to explore the participants' clinical experience by interpreting it in relation to their 'everyday and embodied thinking that incorporates background knowledge, emotional feeling, imaginative scenarios and reflective cognition' (Polkinghorne 2004:130) together with the aspects or dimensions of the life-world described earlier by Ashworth (2003).

The IPA and reflective life-world approaches have enabled me to describe and elucidate the lived world in a way that expands understanding of human being and human experience (Dahlberg et al 2008:37). This move from an exclusively IPA approach to one incorporating elements of the reflective life world approach supported my PhD journey both of living with and understanding the participants' experiences but also of challenging my own theoretical and philosophical assumptions. This more eclectic approach helped achieve important understandings from the participants' experiences that may be relevant to other consultants and further enhance understanding.

Finally in analysing the interview transcripts a small number of, what Polkinghorne (2004) calls, 'little gems' relating to the participants stories emerged as being influential in their experiences and consequent professional practice. It is one such 'little gem' that will be explored in greater detail in section 10.4 of this chapter.

### **10.1.1 Theoretical contexts – setting the scene.**

In this thesis the physicians describe their professional and personal experiences in practice, demonstrating know how and understanding. Know how or tacit knowing is the understanding of what to do to accomplish a goal, relying on multiple sources of knowledge. For the consultants it was their background and experience that gave it meaning and informed their activity. There was an element in all the interviews of physicians in all specialities trying to balance the technological elements of their practice with a more personal and humanising approach to their patients. This was more challenging during transitions of care from curative to palliative, from an active to passive role. In this thesis there appears to be a complementarity rather than a significant distinction made between the physical, scientific and human realm. All participants associated palliative care with death and cancer.

Bourdieu (cited in Jenkins 2002) in explicating his theory of practice describes the concept of 'habitus'; the confluence or melding between the individual and the structure in which they practice. In this thesis the physicians are dealing with the complexity of individual human beings experiencing and involved in difficult and sensitive situations at the end of their lives. In order to provide bespoke care they need to acknowledge the influence of their personal histories and the context of care.

The consultants acknowledged scientifically validated and evidence based knowledge as part of their practice but recognised the limitations of this, at times, reductionist approach. Their practice was informed by ongoing professional development and acknowledged the economic and resource constraints present in contemporary health care.

### **10.1.2 Typologies of knowing and knowledge**

The analysis of experiences described in the interviews demonstrated typologies of knowledge and knowing consistent with the literature. Their knowledge appears to resonate with ways of knowing derived from nursing literature: empirical, aesthetic, personal, ethical and emancipatory which encompasses socio-political and cultural dimensions (Carper 1978; White

1995; Chinn & Kramer 2008). These five dimensions or patterns of knowing were described earlier in Chapter 3.

An initial attempt was made to develop a matrix of knowing that tried to categorise the factors influencing the consultants' referral practices to SPCS under the relevant headings:

Empirics:

- Prognostication
- Disease Type
- Trajectories
- Clinical skills

Ethics:

- Ought to do
- Best/right to do
- Equity
- Choice

Aesthetics:

- Meaning of the persons situation
- Individual variables
- Understanding / Connections

Personal:

- Own personal/professional experiences
- Awareness
- Relationships and responsibilities

Emancipatory

- Resources
- Political/Historical
- Cultural
- Geography
- Organisational context

This reductionist categorisation was helpful in some instances but I am aware that it was also an artefact, as my initial categorisation of prognostication as empirical is unhelpful. The personal elements of knowing appear to influence all the other dimensions. Later discussion in this chapter highlights that it is multifaceted in demonstrating the other four dimensions of aesthetic, ethical, personal and emancipatory knowing together the dimension of 'unknowing'. Unknowing is about uncertainty and intuition.

Empirical knowing was demonstrated by the consultants in each of the clinical specialities. The cardiologists appeared self contained as a group, their understanding of the specific elements of heart failure demonstrated aggregated empirical and technical knowledge of the subtleties and complexities of heart failure; however the critical incidents or reflective examples also highlighted their expertise in managing uncertainty. The cardiologists all describe their expert care in heart failure as being about knowledge of trajectories and transitions. As discussed earlier, the heart failure disease course is unpredictable and diagnosing the end stage is difficult, complicated by co-morbidities and the determining of reversible and irreversible causes for patients' decline.

Empirical knowing was also demonstrated by the oncologists and old age psychiatrists in their description of the therapeutic options and specific management strategies intrinsic to their speciality. For the oncologists it related to the benefits and burdens of active interventions such as chemotherapy and the recruitment and participation of their patients in clinical trials. For the old age psychiatrists it related to withholding and withdrawing interventions, for example, artificial hydration or antibiotic therapy. This links with the ethical dimension of practice relates to the distinction between what they can do as cardiologists and what they should do, in a desire to halt or reverse critical illness and support life but not prolong dying – the benefits and burdens. Dan describes that for the heart failure patient a sudden death is positive whereas a prolonged death is negative. Their decision-making process in relation to the transitions between active and palliative care is characterised by uncertainty and emotionality and involves patients and families.

The aesthetic element of knowing was apparent in the oncologists' described awareness of the meaning of a cancer diagnosis, the positive and negative implications of a palliative care referral and the unique nature of the individual illness experience. The shared understanding with their patients, of the impact of a cancer diagnosis as being a death sentence (albeit often mistaken on the patient's part) appeared to sensitise the oncologists into more of a

partnership approach toward clinical interventions. This was limitedly present in the experience of old age psychiatrists, who were more prescriptive in their approaches to medical interventions. In part this is likely to be related to the nature of dementia and the associated mental decline that often precluded the establishing of a more reciprocal relationship. However there was, in their stories, a clear awareness and understanding of their patients' predicament, that it was a distressing condition that demanded a more ethical approach to care.

For the cardiologists, clinical intuition and aesthetic knowing appear intrinsic to their clinical judgement and decision-making and this is especially characterised in reflections of patients they have cared for. Specifically, Alex describes a lady who travels long distances to the cardiac centre fortnightly in order to have a paracentesis (withdrawal of fluid from a body cavity) to drain the ascites (fluid) associated with her right sided heart failure. He describes the burden of this active intervention on her and her family and is clear that there is therapeutic benefit from this treatment but the associated burdens suggest that extra support would be helpful, especially for the family, although he was reluctant to suggest it for fear of causing distress. There was a felt sense of him being more professionally comfortable with the more interventionist aspects of cardiology. He is clear that heart failure nurses would be better positioned to explore palliative care issues with heart failure patients.

The elements of socio-political knowing identified, suggest that in this thesis, related to the consultants' experiences it is more critical and central than that previously described as emancipatory by White (1995). It relates to the organisational and clinical levels of care delivery, the macro, meso and micro structural levels of health care (Pilgrim & Rogers 1999) and clinical mindlines.

### **10.1.3 Knowing in practice.**

Unlike cancer, the cardiologists believe that a diagnosis of heart failure does not equate with patients recognising that they have been given a terminal diagnosis, there is less public understanding of heart failure. Although the



nomenclature of heart failure, for some people, suggests a sudden event in which the heart stops there is often the perception that something can be done. There appear to be many therapeutic options. For Dan, however, it is a disaster if a patient with heart failure dies in an Accident and Emergency department; although the co-morbidities associated with heart failure can lead to a precipitate event 'which tips them over the top very quickly', which is perceived as a 'good death'.

Their knowledge base is clearly linked to both personal experience and expert specific knowledge. In relation to cardiology this appears to be a mechanistic type of knowledge related to how the heart works, failure of the heart impacts on other bodily systems in the physiological way. Their ways of knowing appear to be related to the length of time they have been consultants and their experiences of particular patients in their care. The unpredictability of the disease trajectory in heart failure encourages them to be more acutely aware of the subtleties of change in their patient's condition and potential reversibility or not of these changes. In their stories they talk about the differences, binary oppositions between light and dark situations or situations where there is a requirement for active as opposed to passive interventions. (Binary oppositions are discussed more fully in Chapter 11).

All the cardiologists and old age psychiatrists describe a 'gut feeling', a bodily sense that encourages them to think that their patient is declining. As a consequence the preferred option for Chris and Dan is to consider starting the patient on the Integrated Care Pathway (ICP) for the Last Days of Life (WG 2011b), although not always helpful it appears to provide a framework of care that supports their idea of 'managing death'. Their description of the use of the pathway seems to negate any responsibility for their patients decline; it seemed to absolve them from mistaken or inaccurate prognostication and the consequent patient or family distress. The pathway seemed to work as an *aide-memoire* or checklist for end of life care, perhaps distancing them from the personal impact of the patients' deterioration.

The ICP, from the cardiologists' perspective, also appears to have an additional function in that it is perhaps a vehicle supporting shared decision-making in relation to advance care planning, enabling the transition from active to palliative care (Coulter & Collins 2011). It enables the communication of information related to the changing focus of care, treatment options and the benefits, burdens and uncertainties associated with end of life care. As the ICP is a validated document that has been endorsed at national governmental level (WAG 2006) it might also protect the consultant in that the 'diagnosing dying' decision may not be seen as exclusively theirs, again absolving them from responsibility for the consequences.

The old age psychiatrists in preference described the use of routinised or familiar knowledge such as supporting the withholding or withdrawing of treatment together with new emerging evidence such as the use of care pathways as a way of facilitating the transition from active to palliative care. Mair gave a clinical example of a patient being on the care pathway for a protracted period as being problematic for the family and difficult for the team who felt a burden of responsibility of almost prematurely predicting the end of life. The concern related to this was minimised by her assertion that the pathway supported the patients comfort.

The care pathway supports both the dimensions of evidence based practice in relation to providing prescribing and DNAR guidelines but also pays attention to holistic needs (emotional, spiritual and financial) together with the human aspects of care such as ensuring relatives have access to car parking and beverage facilities. Its development and application suggest it is more akin to a clinical mindline than a pathway due its dimensions of eclectic evidence, experience and responsiveness to change that supports clinical 'capability' in dealing with complexity (Fraser & Greenhalgh 2001; Gabbay & leMay 2011).

In this context capability is:

The extent to which individuals can adapt to change, generate new knowledge, and continue to improve their performance.  
(Fraser & Greenhalgh 2001:799).

None of the oncologists talked about the use of the care pathway, most were able to identify when their patients cancer was no longer curative. They were able to give clinical examples that evidenced a downward progression, implying that death was imminent and described their consequent practice being focussed on comfort measures. This was encouraging in that the ICP was specifically developed for improving the end of life experience for people with advanced cancer, focussing on streamlining prescribing and the discontinuing of unnecessary interventions. It appeared from their descriptions of practice that the philosophical and practical aspects of the ICP were inculcated and intrinsic in their routine practice.

Some of the cardiologists appeared slightly demeaning of the knowledge base of their palliative care colleagues, Ben describing the role of palliative care as providing analgesics, sedatives and anti-anxiety medication. An attitude which appeared to negate the holistic element of palliative care and suggested that the skills required were not as valuable or of equivalent complexity to those of a therapeutic cardiologist.

The oncologists and old age psychiatrists' were in contrast, more respectful of their palliative care colleagues' unique expertise and valued their skills in direct patient management or as a clinical resource. They see them as especially skilled in dealing with complexity, whether that is the physical, for the psychiatrists or the psychosocial for the oncologists, elements of palliative care.

For the cardiologists the commonality of their experience related to their specific clinical knowledge, their uncertainty and wariness in relation to diagnosing dying. The experiences lived and felt by the cardiologists suggest they have a shared understanding of their specialist knowledge base, enabling them to function at an expert level. They appear certain that their own speciality has primacy and share a certainty of professional knowledge that accords them almost privileged status. As a group they were, perhaps, a little 'showy' in their description of their therapeutic skill sets including 'medical and device therapy', 'high dose diuretics', dealing with the causes from 'a

cardiovascular perspective and vasodilate' and in describing the complexity of heart failure they identify the consequences of worsening heart failure as likely to cause, for example, fluid retention, pulmonary oedema and renal failure. They all appeared certain there would always be some therapeutic option available; ethical knowing related to considering the potential benefits and burdens of these treatments, often influenced by personal experiences and particular cases.

External factors, emancipatory knowing, made all consultants question their current practice, much of which was compromised by finite resources and the macro and meso levels of the organisation who in the cardiologists' experience acted as a barrier to necessary service developments such as the employment of heart failure nurse specialists. This was explored in greater detail in the previous chapter.

#### **10.1.4 Clinical thinking.**

Interpretation of the interview transcripts explored the relationships between the types of knowledge (procedural, propositional, practical, tacit, skills and know-how) and its significance for professional work. Clinical thinking for all the participants appears influenced by illness scripts, mainly limited to technical and practical knowledge, 'rules of thumb' that appear to have evolved from complex prior experiences and the consequent reflective thinking and heuristics. A more pragmatic approach draws on well used thought patterns firstly identified by Dreyfus & Dreyfus (1980) that support making spontaneous judgements when rational decisions are not possible or feasible.

These ways of knowing were not sufficient to demonstrate the totality of their clinical thinking and knowledge in practice. It enabled them to demonstrate their knowledge in a specific situation, such as their clinical speciality, but it was not adequate in clinical situations that were less familiar to them, for example, when thinking about their knowledge in practice in the context of care at the end of life.

In an additional way of supporting understanding, Erauts' (2007) framework was considered, as it specifically attempts to identify the tacit dimension of expertise which includes the domains of understanding, skills, knowledge and decision-making. It was acknowledged at the outset that what is tacit may be difficult to discern; his framework was used as a prompt when exploring the interview transcripts for patterns and connections in the consultants' experiences and in supporting the discussion. It was specifically linked to the clinical issues of prognostication and therapeutic interventions and enabled me to understand more of their experience. Chapters five through eight descriptively and interpretatively demonstrated the consultants' individual and shared understanding, clinical skills, knowledge use and decision-making.

In summary, their understanding was demonstrated in the interviews by reflection on implicit and incidental learning, together with an embedded collection of knowledge derived from experience and particular episodes of care. They demonstrated expertise through the accumulation and practice of routinised skills, clinical intuition and capability (Dreyfus & Dreyfus 1980). Their high level knowledge use was evidenced by transforming and resituating knowledge, retrieving knowledge from memory, recognising when to use some knowledge and sensing how to use some knowledge (Gabbay & leMay 2011). Their decision-making was rapid and intuitive based on holistic assessment and judgement in complex uncertain situations (Benner 1984; Eraut 2007). It was complexity that characterised their interviews, complexity related to their personal and professional experiences, and related to their patients situation and specifically end of life care. This was compounded by the increasingly complex arena of health care practice.

Sweeney & Griffiths (2002) believe that NHS organisations, professionals, patients and diseases all contribute to this complexity. As discussed earlier there are elements of paradox and confusion contributing to complexity. Post-modernism, for example, challenges the primacy of science, its information base is being disputed by relativism and the different typologies of knowing. The increasing involvement of patients in shared decision making and inter-professional working also appear to be undermining the dominance of the

scientific approach (Plsek & Greenhalgh 2001; Coulter & Collins 2011). These complexities are particularly evident, as described in the consultants' stories in this thesis, for the clinician dealing with metaphysical problems of care at the end of life.

## **10.2 THE LIFE-WORLD**

Chronic or life-threatening illness affects one's engagement in the world and also portends the inability to carry out future projects or achieve anticipated goals (Toombs 1993). For the consultants, the impact of understanding and being with their dying patient's situation appears to polarise their approaches to end of life care. They appear to either view it as something dark and pessimistic and to be avoided, as characterised by Alex's story, commonplace and to be expected as described by both Ian and Mair or as a situation or experience to be managed which was the essence of Chris's account.

The reminder of one's own mortality when dealing with those at the end of life rarely emerged in their narratives, this may have been due to professional detachment or their pragmatic view that dying is an essential part of living and being in the world. Chris was the only participant who, when talking about his own death, indicated he would like it to be as late as possible, that he was 'death denying'.

Life-world's focus on experience is not exclusive, what is unique are the aspects or fractions proposed within the life-world approach which provide a framework and focus for the researcher on describing the breadth of the consultants experience. In exploring the life-world of the consultants it is their perception, experience and intentionality that is being considered, how they relate to and acquire knowledge in their world. Early in the thesis, other philosophical and theoretical concepts emerged as having the potential to explore the consultants' experiences, these will add support to the following discussion.

Ashworth (2003) suggested that although the way we experience the elements of the life-world will be unique for each of us, certain aspects of being alive are universal, they are the parts of the life-world that are experienced fluidly, with each aspect of the life world influencing and being influenced by the other. As described earlier in Chapter 3, these fractions of the life-world are not separate but are an interconnected part of the whole. These elements are located within the life-world as being formed not by the 'things themselves' but from the 'constitutive activity of the mind' (Hodge 2008). They are the how things appear in our life-world, in our shared and idiographic experience (Smith et al 2009).

Ashworth (2003) initially identified seven aspects of the life-world which together with Finlay's (2010) typology of the five intertwined structures or levels of 'being-with' were particularly significant in achieving a more complete understanding of the consultants' individual experience. This life-world approach involved a reframing of practice, seeing and hearing it differently, which in turn impacts on and supports understanding of it: 'so the process of perception is a unified process in which observation *is* interpretative, and this is reflected in the language, in particular in changes in metaphors' (Russell & Munby cited in Fish 1998:165). The language and discourse used by the consultants to describe and live their situation will be discussed later in Chapter 11 focussing specifically on their use of metaphor.

### **10.2.1 The life-world in practice**

Commonalities of experience are apparent when considering and 'reframing' the life-world of medical consultants, this also links with the concept of habitus in that there is a shared context in which their world is located (Jenkins 2002). In exploring the life-world elements of the participants shared experiences will be discussed, most relate to the health care context, the environment of care and their personal and professional experiences. It is congruent with the philosophy of IPA and is synergic with much of the elements supporting its approach to data analysis.

In relation to embodiment, for the participants their professional situation brings them into daily contact with people nearing the end of life, this may evoke for them past personal and professional experiences together with confronting their own mortality (this is linked with the idea of temporality). Embodiment may force them to consider the more overt bodily changes such as the deterioration associated with heart failure, dementia and cancer as well as the more hidden 'lived body' changes associated with progressive disease. For example, the fatigue associated with both advanced cancer and heart failure is not just a symptom of disease it is an obvious expression of the patients' lived experience of the illness and impact on their being in the world.

The consultants' stories and reflections demonstrate awareness and shared understanding of the more holistic impact of disease on their patients and how their life-world was changed by illness. It is possible that their (and our) own experience of the life-world is altered and influenced by watching the life world of others being compromised. The implication for practice is uncertain but perhaps supports a more reflective and humanising approach. Acknowledgement of this uncertainty impacts on the consultants' sense of self, their agency and identity - Who they are, what they do and what is its influence on the life of others.

The relational elements of the life-world impact on palliative care referral, in that palliative care referral requests from heart failure patients and their families are unusual. Those referred by the cardiologists and old age psychiatrists are highly selected, most are linked to individuals with additional diagnoses or to facilitate quick access to particular aspects of care. Some of the examples being given in the interviews were for community support to enable the individual to die at home, for psychological support or for specific pain management interventions.

The sociality and relational dimensions also build on acknowledgement of their own and the patients' situation which potentially impacts on their clinical judgement and intuition. In their interviews they support more judgement-based approaches to health care and demonstrate the tacit elements of expert



practice. This is evidenced by the oncologists' reflections and experiences that in cancer care there is more of a shared approach with palliative care. In this thesis the consultants' awareness relates to their personal and professional experiences related to end of life care and how it is manifest in clinical practice. An example of this life world fraction is how Chris' experience of his mothers' death, as being a managed and precipitate event, has influenced his approach to his patients. Specifically for his patients he recognises that he has the skills to 'manage death' and seeks not to prolong life. This links with personal and professional biographies and the ways of knowing discussed earlier together with the life-world fraction of temporality.

The sociality and relationality dimensions together with spatial (the impact of place and space on their situation) and project (their consultants' role which is central to their lives) aspects of the life-world also link with and are influenced by the context of health care, the macro, meso, and micro levels in which consultants practice is embedded. They are required to function at all levels which have an impact on their practice which is by turn's complex, dissonant and enabling. All the consultants describe the tensions in practice between the care of the individual patient, their patient group as a whole and meeting the organisational and strategic requirements of the LHB and national government.

An example of this is described by three of the cardiologists, they identified that their care of the person with heart failure is influenced and compromised by inadequate resources, the lack of heart failure specialist nurses and the reticence of the LHB to identify this as a clinical priority despite the offer of funding from a voluntary organisation. The oncologists illustrate this tension with reference to the location of the local hospice being at a different hospital site from that of the cancer centre, this has an adverse impact on their working practices and in supporting seamless patient care. The old age psychiatrists allude to this tension in relation to their own professional practice in which as consultants they are more absent from their dementia patients' journey, as there is an organisational requirement for their inpatient services

to provide acute care with continuing care being provided in the community or nursing and residential homes.

The mood element of the life-world relates to how we are in the world, it is a way of understanding the meaning of our situation, it links to the idea of clinical heuristics, the 'gut feeling' of how things are in practice. For the consultants this is the sense that something is wrong in practice that is not linked to any clinical evidence that links with tacit knowing.

The attempts to explore the aspects of the life-world individually were compromised by their inter-relationship and complementarity. In the consultants' descriptions of their experience each aspect informed and enhanced understanding. The process, 'encouraged a level of reflection and understanding in which both the shared and unique dimensions of peoples' experiences are communicated' (Todres et al 2007:58).

This life-world approach supports the concepts of ways of knowing and ways of being that attempted to identify the human element of the consultants experience and its influence on their practice.

### **10.3 JUDGEMENT-BASED PRACTICE**

Medical knowledge, as made clear in the consultants' stories, is inherently uncertain (Sturmberg & Martin 2008). It appears from the consultants' experiences that they attempt to manage uncertainty in parallel with employing evidence-based clinical judgement. This supports a more humanising approach in their clinical practice and enables them to function at all levels of health care practice.

Judgement-based practice promotes the belief that practice uses professional judgement in order to accomplish a specified goal. Practitioners' self-knowledge, experience and training will enable them to make flexible judgements about what actions will achieve a specific goal with a specific person at a specific time in a specific place. Judgement-based practice focuses on the practitioner as being the unique factor that enables the

achievement of the goal of care, for example in the establishing and communicating of an end of life prognosis and facilitating the transition from curative to palliative care. Judgement-based care is suggested as being more flexible and responsive to individual difference and practice uncertainty. The literature suggests that it is the knowledge, skills and the relationships with patients and families that are uniquely valued and prized by practitioners. This human approach was apparent in the interviews and is congruent with the philosophy of end of life care.

An embodied approach to thinking and knowing supports a more unique approach to care, this approach was implicitly present in the interviews with many of the participants. For all the consultants their clinical role was characterised by judgement-based approaches to care that was a gestalt of practical wisdom, knowing, experience and clinical intuition in practice.

As in much existing literature what emerged from detailed analysis of the interview transcripts is a universal sense that for all the consultants, end of life care is not merely a technical activity or undertaking. The experiences of care they describe are congruent with what Polkinghorne (2004) calls 'judgement based care'. As discussed previously there were a number of participants, though not the oncologists, who supported the use of the integrated care pathway for the end of life as facilitating end of life care. However, all contextualised this with acknowledgement of the caring elements, that the use of clinical judgement and knowing was intrinsic to its use and that it relies on accurate prognostication which is clinically and technically problematic in determining the last days of life.

There is an understanding of the 'centrality' of professional judgement in the consultants' descriptions of their experience, yet they all find it difficult to precisely explain or articulate what it is. This is consistent with much of the literature which also recognises that not all judgements made by professionals are appropriate or that departing from guidelines and protocols will lead to improved health care (Gabbay & leMay 2004; Sturmberg & Martin 2008; Gabbay & leMay 2011). The quality of patient care often depends on the

appropriateness of the clinical judgements made, these judgements rely on professional responsibility (moral, ethical and practical), and are often made intuitively with little time for discussion or reflection.

### **10.3.1 Clinical decision making**

In considering the clinical decision making and gate-keeping role of medical consultants in relation to referral to SPCS the work of Bourdieu is acknowledged, in particular his idea of 'habitus'. The skills of 'habitus' he believes are required for functioning successfully in society or a particular society (Jenkins 2002). In this thesis the specific society is the health care arena. However, as described in the participants' stories, 'habitus' is often a routine way of behaving or being which is often unquestioned because of its inherent nature. Thus it was more hidden in the consultants' stories.

The patterns or inclinations that guide behaviour and thinking are demonstrated by the shared experiences of the cardiologists and oncologists, this may relate to all the participants working within cardiac and cancer tertiary centres with apparently homogenous clinical and organisational structures influencing, to some extent, their medical practice.

These shared behaviours and experiences are less apparent in the interviews with the two old age psychiatrists, it may be linked to their significant differences as individuals and the fact that both worked in different clinical and organisational Health Boards that were adjacent geographically but appear to have developed their specialist services in a different way.

Our 'habitus' is socially constructed, transferable, evolutionary and 'can be changed under unexpected situations or over a long historical period' (Navarro 2006:16). This is evidenced by oncologists who described experiences where the historical evolution of palliative care with its shift in focus from care of the dying towards more active interventions in managing complex symptoms throughout the patients' disease journey has had an impact on the way they use palliative care services. It has made Greg, for example, less certain as to its place in the cancer journey and question the appropriateness of the referrals he makes.

The change in focus of palliative care has had less impact on the cardiologists and old age psychiatrists who still believe in the cancer dominant focus of palliative care. Their challenge is characterised by uncertainty as to where palliative care fits in their patients' journey or whether it does have a role directly in their patients care or whether it is a resource for them. Their situation is compromised by strategic and organisational recommendations for palliative care to be made available to their patient populations.

This embodied relational understanding together with 'habitus' builds on the foundations of qualitative research which have impacted on healthcare practice and policy. Its unique focus directly privileges everyday practice and the practitioners' striving to provide compassionate quality care. This is resonant with the aims of this thesis with its focus on the physicians' individual and shared unique experiences (Kúpers 2005; Morse 2006, Sandelowski et al 2006; Todres 2008).

#### **10.4 LITTLE GEM**

In exploring the interview transcripts a particularly (lengthy) incident in Greg's early career just 'jumped out' at me as being the essence of his being and his practice, that appeared to be the foundation for his role as an oncologist. All the participants described the importance of professional role models as being influential in their career development. Greg's experience is unique as he had not described it in its entirety outside his immediate family circle. The story was valuable as it was based on what appeared to be a negative incident that had a positive outcome influencing his choice of clinical speciality and consequent approaches to his dying patients. Sadly for Greg his preferred career choice palliative care was not an option as it was not an acknowledged speciality thirty five years ago, oncology was perceived by him as the closest option and he felt it difficult to change speciality when an established consultant. His description of his practice clearly demonstrated an integration of palliative care into his practice as an oncologist.

From a personal, idiographic perspective Greg described, in depth, a very powerful critical incident as influencing his career choice when he was a senior house officer. The narrative conveys the holistic impact on his senses; what was said, how it was said, how it felt, how it impacted on his subsequent practice and his way of being in the world:

When I first qualified, I wanted to be a surgeon and then when I did my first house job with a *[consultant]* surgeon who had not long been appointed, he was appointed two days before me *[starting my SHO job]* and he was bonkers. He, as I realised later, was manic depressive and he would come in at two o'clock in the morning and wake me up in the doctors' residence and say "come on let's go and do a ward round". He'd go down to the ward wake everybody up, get the nurses up and do a ward round. In theatre, there would be scalpels hitting the wall, he'd be hurling stuff across the hall, abusing everybody, all the nurses would be in tears. I'd be stood there thinking why am I doing this? Am I crackers? Is this really what I wanted to do and stand here being abused by this nut case and he was the first consultant I'd worked with and I was beginning to think are they all like this? And then as you walked out of theatre he'd put his arm around your shoulder and say "well done, very good" having told you that you were lower than a worm for the last two hours. He was bonkers!

Within the second week of my job we had this delightful man who was only in his thirties who came in with lymph nodes and he, my surgeon took him to theatre to biopsy them, this was progressing extremely rapidly. Biopsies came back, but up until the histology came back we would do the ward round and this surgeon would sit on his bed talk to this guy "oh we're still waiting for the results as soon as we know what the results are we'll know what we're doing

After further prompting he continued...

he came back, highly malignant, rapidly growing and the patient was fading away in front of us. From the moment the histology came back this surgeon would not talk to this guy. He would do the ward round, he would speak to every other patient but he would sail straight past the end of this guys bed, no communication with him, whatsoever. The man would say 'Mr Ellington, Mr Ellington' *[name changed to protect him]* and the guy would ignore him. Right, this was my second week in the job and I did not know what to do. I spoke to the night sister, who was a very sensible lady and she said "it's perfectly obvious what you do, you ignore your surgeon

(‘cos he’d said ‘no, no he’s just going to die just leave him). Speak to the oncologist they’ll come and see him and they’ll talk to him and explain things to him”. So I rang this oncologist and told him exactly what had happened and how the surgeon wasn’t doing anything, and the oncologist comes around, sits on the patient’s bed, puts his arm around the man and said “lets talk about what’s wrong” he was, it was about six o’clock at night and he was there till about eight, and I immediately changed my mind and decided that was what I wanted to do, I did not want to become a surgeon anymore and probably if there had been palliative care at the time I would have done it then, instead of doing oncology (Greg).

In exploring this story there appear to be a number of layers of interpretation. At the descriptive level, the story is presented as a critical event that shaped his future direction. The narrative was characterised by an almost angry tone, the words used to describe the surgeons’ words related to his poor mental state and were derogatory and vernacular ‘bonkers’ and ‘nut case’; his behaviours in the operating theatre were violent and unpredictable ‘scalpels hitting the walls, he’d be hurling stuff across the hall abusing everybody, all the nurses would be in tears’, telling you, you were ‘lower than a worm’. This language made him very lifelike, almost a caricature, and appeared to reflect Greg’s powerlessness and impotence in the situation. Greg used the diagnostic label ‘manic depressive’ as a way of explicating what was unacceptable in this experience, although this label only was applied later following reflection. The surgeons’ behaviour in relation to a particular patient was characterised by inadequacies of knowledge; whilst waiting for specific diagnosis channels of communication were open but as soon as unpleasant knowledge was known there was no further contact, the relationship characterised by complete avoidance. Greg’s description of the patient and oncologist was characterised by a softer tone of voice and a more gentle account. What appeared memorable were the personal and comfort aspects of the oncologist’s approach to a delicate situation.

The key aspects of his experience link with the life-world, the fractions being present (Ashworth 2003) and acting as a catalyst for understanding his

experience. For Greg, his career path as a surgeon was clear, this initial experience as a house officer was to confirm this choice and provide him with the necessary clinical skills to become a surgeon. His story describes elements of practice that were troubling: the consultant was a poor role model with behaviours to his colleagues, team and patients that impacted on his and their ways of being, relationality and discourse. It also highlights the surgeons' volatile and capricious nature and the consequent impact on all around him. Highlighting the negative impact on others, the surgeon, on a persons' way of being and life world and alternatively by direct contrast the positive impact of the oncologist.

The night sister, a more experienced member of the team, advised a strategy that focussed on the needs of the patient, but also provided Greg with a role model that was a catalyst for change. The communication and human skills demonstrated by the oncologist were a powerful exemplar of the human, 'invisible' elements of practice. For Greg, the life-world element of 'project', his chosen career path and perceived professional role as a surgeon was impacted on to the extent that his 'immediate' response was a change of career direction. The choice of oncology was made, Greg reflected that his preference would have been palliative medicine but it was not an acknowledged or available speciality at that time. The story of his clinical experience is characterised by examples of palliative care philosophy and skills being integral in his day to day activity and in the relationships he maintains with his patients and families. He works as a trustee and medical advisor for a local palliative care charity which demonstrates his commitment and ongoing enthusiasm.

## **10.5 CONCLUSION AND SUMMARY OF THE DISCUSSION**

In considering the theoretical context, the consultants' knowledge in practice and clinical thinking, the following question was at the heart of the discussion: *Does professional specific knowledge benefit the service user or the profession it represents?* From the discussion it is clear that there is almost a mutual benefit in the acquisition of knowledge that benefits both and supports what is described as appropriate professional behaviour and is recognised by



the professionals themselves. This is described by Lupton (1997) who asked doctors to identify the templates of appropriate professional behaviour:

While they may also have emphasised expert knowledge and judgement of uncertainties as important, the doctors typically articulated the importance of practising a medicine that was empathetic and involved good communication between patient and doctor, including the doctor being able to listen to the patient and be genuinely interested in the patient's feelings and symptoms (p490).

This links back to Aristotle's primary philosophical argument that the good life is lived among the realm of the changing and contingent, as summarised by Polkinghorne (2004). Clinical reasoning is supported by *phronesis* deliberating on activities that seek to do good in a particular situation, *praxis* (clinical practice) is based on actions, doing the good with the outcomes relating to a good action. This supports the requirements of ethical, professional practice that is intrinsic to the multi-layered and complex nature of being a doctor.

The themes which supported the discussion in Chapter 9 were related to the structural context of specialist palliative care (as outlined in Chapter 2 of the literature review): historical and political background, clinical diagnosis (cancer, heart failure and dementia), disease trajectories, prognostication, patient and physician perspectives. The theoretical context (described in Chapter 3, the second part of the literature review) provided the lenses used to explore and understand the data in this chapter. These were the conceptual frameworks of knowing, knowledge, expertise, competence, the life-world and judgement-based practice.

In exploring and understanding the consultants' stories of their experience there appears to be complex interplay between:

- The participants' broader perceptions of palliative care (SPC) as a treatment modality.
- The specific issues and knowledge base that relate to their own clinical speciality (positive and negative constructions) especially in relation to trajectories and prognostication.

- The participants' personal and professional experiences of death and dying.
- Patient and family variables, consideration of the difficulties they are experiencing, and the impact on referral.
- Clinical knowing and thinking especially in relation to referral decisions and their evidence base 'why, when and how'?
- The impact of macro, meso and micro level of health care organisation and delivery on their professional role.

In the next chapter these complexities will be further explored by considering the participants' use of language as a way of achieving a more complete understanding that links with the thinking approaches associated with the hermeneutic circle.

## **CHAPTER 11- LANGUAGE AND METAPHOR.**

**Experience exists outside language but can't be described without it. (Weedon 1987).**

### **11.1 INTRODUCTION**

This chapter evolved from awareness, during the analysis of the participants' interviews, that metaphor and specific elements of language were commonly used by the participants to describe their experiences. Their experiences may exist outside language but as Weedon (1987) points out, it required language to articulate that experience to other people, to make that experience more easily understood. This linguistic interpretation of the consultants' experiences will concentrate on language and metaphor (Smith et al 2009) and binary opposites and poststructuralism (Derrida 1973; Chandler 1994; [www.englishbiz.co.uk](http://www.englishbiz.co.uk) [accessed 3/10/2011]). It is linked to the post modern belief of multiple truths in that there are a diversity of meanings and understandings making up the person's life-world, these being contextually, historically and culturally influenced, linking back to Gadamer's historical approach to the phenomenological interpretation of texts. Thus the IPA thread and focus is maintained.

In the interviews for this thesis the function and use of metaphor appeared rhetorical, semantic, conceptual and ontological. Metaphors were used to establish a shared understanding and it appeared at times that they were specifically used to make ideas that were difficult emotionally to express, accessible to me and a potentially wider audience. As I became more deeply immersed in exploring my participants' experiences I became aware that the relationship between experience and language was a fundamental one for me, in achieving understanding of their experience.

My attempt to achieve linguistic understanding, I think was compromised by the 'poststructural' dichotomy that the meanings of words are embedded in the person's deliberate choice of language but achieving understanding of the precise meaning of their words and hence (in this instance) their experience is problematic as the language used rarely conveys the complete sense or

meaning. As Derrida (1973) points out the use of language does not give the whole picture, something is often missing.

To structure and make this part of the analysis manageable the following question was used to guide this chapter of the thesis:

How might a focus on metaphor and other linguistic devices contribute to understanding the participants' experience and its meaning to the participants?

This question was derived from Shinebourne & Smiths' study of the language of addiction (2010) and supports the double hermeneutic activity advocated by IPA (Smith et al 2009).

## **11.2 THEORETICAL BACKGROUND.**

Historically, semiotic analysis developed to facilitate the exploration of the signs (words, images, sounds) intrinsic to everyday speech. Contemporary linguists acknowledge that it now encompasses the importance of the meanings of the signs. Semiotics is more theoretical than empirical, with authors struggling to achieve consensus and establish its scope and general principles. Competing theoretical assumptions are prevalent with multiple definitions but most acknowledge that:

Semiotics is important because it can help us not to take reality [*or experience*] for granted as something having a purely objective existence which is independent of human interpretation. (Chandler 1994:16).

In IPA, and for this thesis, the specific purpose of exploring language and metaphor use by the participants in their interviews is to provide an adjunct, or supplement, to their descriptive and interpretive accounts. Metaphor and binary opposites specifically helped the participants articulate their experience and provided rich ways of illuminating their stories.

Specific linguistic elements are rarely quantitatively valuable, for example focussing on the frequency with which a phrase, word or linguistic device occurs in the text is less important than the qualitative significance of their use in describing, understanding and clarifying experience. A 'social semiotician'

would emphasise the importance of the significance which readers (interpreters) attach to the signs within the text. A 'structuralist semiotician' is more concerned with the relationship of elements of language to each other, they focus on the language itself seeing it as the most fundamental and powerful communication system that acts to signify meaning. The structural semiotic elements were concentrated on when exploring the participants' interview narratives for this thesis.

Metaphor, analogy and metonymy are generally accepted as the figures of speech most fundamental in communicating meaning and forming the basis for much of our understanding in everyday life (Jakobson & Halle, Lakoff & Johson cited in Chandler 1994).

Metonymy relates to the substitution of the name of a feature for that of the thing intended, for example 'crown' equates to King (or Queen), there were no incidences of metonymy being present in the consultants' stories so it will not be considered in this chapter. Analogy is defined as being a similarity between like features of two things, on which a comparison may be based. For example, in this thesis the cardiologists made the analogy between the heart and an engine. Analogy will be more fully explored later in the chapter.

Metaphor relates to the change of sense and meaning from one situation to another, it is the most basic foundation of metaphorical language, Aristotle cited in Sontag (1989) describes it as 'giving the thing a name that belongs to something else' (p.91). Specifically considering how useful they may be in illuminating the participants experience; 'shedding light' being the appropriate metaphor; language being the primary way people articulate their experiences, the importance of their use of language and its interpretation is a particular strategy advocated by IPA. Metaphor is especially useful in IPA as:

It is a linguistic device which links descriptive notes to conceptual notes (Smith et al 2009:88).

Binary opposites were also present in the consultants' stories, they are 'one of the most important principles governing the structure of languages' (Lyons

cited in Chandler 1994:271). Binary oppositions are ways of constructing or creating layers of meaning in texts. Saussure (1983) suggests their purpose is to maintain and reinforce a society or culture's dominant ideologies, their shared theory of meaning. They occur naturally in the language of members of the same group.

Therefore metaphor and language together with acknowledgement of the binary oppositions in the consultants' stories will be the focus for this chapter in achieving a more complete understanding of the consultants' experience.

A number of authors highlight the appropriateness of metaphor in expressing and communicating experience in the context of health psychology, nursing and medicine. Clow states (2001) that metaphors are created to explain an experience [situation] as well as being a way of changing, understanding or 'transforming' that experience.

Epistemological implications of rhetorical figures of speech have evolved in the latter part of the twentieth century as a radical challenge to the language of objectivism, the scientific use of language. These rhetorical aspects of language are not simply a matter of how thoughts are presented but also influence ways of thinking. This thinking is allied to nihilistic and relativistic epistemological approaches rather than to rationality and pragmatics. The contemporary stance acknowledges that language is not an objective, neutral medium; therefore its use legitimately shapes experiences enabling interpretation.

The challenge in this thesis resonates with Aristotle's search to find a level of discourse that accurately captures the individual's unique experience and situation, their 'lived world' and how the individual perspective resonates with more general human experience (Todres et al 2007). When describing experience, language is the device in all dialogue, supporting questioning and understanding. In relation to the life-world, experience is made more accessible by a shared understanding of language and the world and, as such, has a valuable hermeneutic purpose. In relation to understanding –

experience, language, being and history are in relation to, and have common characteristics with, each other.

The consultants' stories and language appear to constitute their being and their life-world, enabling them to articulate some of the more existential aspects of their experience (Greenhalgh & Hurwitz 1999). Analysis of their language was, however, attempted with some caution as it appeared to manifest both advantages and limitations in exploring the experience of the consultants and understanding the meanings in their world. The link between language and the philosophy of the life-world is contradictory, being partly transparent in that what is said gives insight into being-in-the-world but is also obscure in that much of being is unsaid and beyond understanding. Thus, there is a potential conflict between language and the life-world which was raised in the previous chapter.

The place of language in the description and interpretation of experience lies along a range between the phenomenological concept that experiences come before language (Husserl 1998), and the post modern idea that 'experience itself is a construction of the language one speaks' (Derrida cited by Polkinghorne 2005). The analogy of an author struggling to find the right word to describe a feeling or thought makes it clear that experience is more multifaceted than language and that it informs and puts right the words people use to express it (Gendlin cited by Polkinghorne 2005). The middle ground, which helps in exploring the experience of participants in this thesis, is that:

Experience is more complex and nuanced than can be expressed in literal language (Ricoeur 1978:147).

He suggests that the use of figurative expressions of speech such as metaphor and narrative will capture the richness of the experience and open up the meanings of that experience.

Bourdieu, according to Jenkins (2002) considers language to be not merely a method of communication, but also a mechanism of power. The language one uses is designated by one's relational position in a field or social space, the implication being that medical consultants with their perceived status and

power (see Chapter 4) would use more powerful language (Lupton 1997). Different uses of language tend to reiterate the respective positions of each participant. Linguistic interactions are manifestations of the participants' respective positions in social space and categories of understanding, and thus tend to reproduce the objective structures of the social field. This determines who has a 'right' to be listened to, to interrupt, to ask questions, and to lecture, and to what degree. On reflection there generally appeared to be an equipoise in my interviews with the consultants in that there was a degree of reciprocity and respect, with neither appearing to be more powerful. The only instance where I felt powerless was in the interview with Ian in which my specialist knowledge related to advanced dementia was clearly perceived by him to be severely lacking.

### **11.3 LINGUISTIC ANALYSIS: THE PROCESS**

The approach used in identifying and exploring how the consultants used metaphor in describing, communicating and sharing their experiences was confluent with the required elements of IPA linguistic analysis. In the early stages of analysis there were metaphors and particular use of language in the interviews that emerged with little effort on my part. They demonstrated metaphorical uniqueness and diversity in describing their experiences, this evolved and became more absorbing prompting me to focus on this aspect of their narratives as part of my analysis. This appears consistent with the approach of other researchers (Elwyn & Gwyn 1999; Greenhalgh & Hurwitz 1999; Charon 2001; Montgomery 2006).

Froggatt (1998) in analysing the descriptive interview accounts of hospice nurses' clinical experiences indicates that often the function of their language and metaphor was 'a symbolic artefact' - of unknown signs or meanings about the more hidden aspects of their experiences that reflected the emotional component of hospice work. Kövecses (cited by Froggatt 1998) highlights the importance of the role of metaphor in studying the emotional meaning of experience, because metaphor permeates the language of emotion, having delicate effects on the ensuing feelings and actions.



The specific focus on metaphor has been explored in contemporary IPA research and appears to help achieve a richer and more in depth understanding of people's experiences (Eatough & Smith 2006a; 2006b; Smith 2008). Often researchers use metaphor in attempting to describe a shared understanding of emotions that are difficult to articulate, for example Eatough describes her participants' feelings of anger with the direct quote 'I was like a wild person' (Eatough & Smith 2006a) or in supporting them attempting to make sense of those angry feelings the process is described as feeling 'like a scrambled egg in my head' (Eatough & Smith 2006b).

In a recent paper Shinebourne & Smith (2010) believe that:

IPA can make a valuable contribution to metaphor analysis as it attends to both the experiential dimension of metaphors through phenomenological analysis as well as to the hermeneutic possibilities opening up through the capacity of metaphors to make connections between disparate ideas and concepts (p 59).

This is demonstrated in their study exploring the experience of addiction. Initially they explored their participants' use of metaphors to express and communicate experiences and emotions, they then engaged in a more critical approach to contextualising and discussing the use of metaphor in the discourses of addiction, thus achieving a shared understanding.

It was Shinebourne & Smith's (2010) paper that helped legitimise my approach to exploring how the participants talked about their experiences, *how* they said what they said, (rather than what they said) which offers another perspective in attempting to achieve the 'double hermeneutic', for me the researcher, trying to make sense of the participant trying to make sense of their experience. I particularly focussed on the participants' use of metaphors in exploring their more personal and problematic experiences in relation to their clinical speciality and to palliative care, death and dying.

At the outset it is important to acknowledge that the participants' narratives may have been a 'cover story', in that they may have said what they believe needs to be heard, or that it may be socially and professionally constructed or

what they believed I wanted to hear. The interview approach adopted (see earlier in Chapter 4) and the subsequent analysis, involved processes to identify as far as possible the consultants real experiences.

The process was undertaken following the descriptive analysis of the individual participant interviews, each transcript was revisited to focus on the language and metaphors used. Its purpose was to facilitate greater insight and understanding by considering the more 'hidden' aspects of the participants' experience. I was particularly seeking to identify possible metaphors related to their clinical specialist areas (cardiology, oncology and old age psychiatry) and to their personal and professional experiences of death and dying.

Various procedures have been developed for conducting metaphorical analysis in the context of linguistics. Todd & Harrison (cited by Shinebourne & Smith 2010) suggest that if the research aim is not purely linguistic, thematic analytical procedures for identifying metaphor might be more helpful in achieving understanding. As this study is hermeneutic rather than linguistic the procedures used in the descriptive and interpretative elements of IPA were also used in exploring the interview narratives. A focussed thematic analysis of the original transcripts was undertaken in order to identify metaphor and other linguistic elements derived by analysing the interview transcripts. The following section explores the individual use of language but also considers commonality in the use of language and metaphor in the shared experience of the cardiologists, oncologists and old age psychiatrists.

#### **11.4 LINGUISTIC ANALYSIS: DISCUSSION**

The individual participants' use of metaphors and language was not always easily discernible. On revisiting the transcripts there emerged much similarity, perhaps reflecting a shared medical culture and professional understanding. This first impression was formalised by explicit clustering of the metaphors and searching for similarities between the specialist groups of participants – this resonated with the specific ways of looking for patterns and

connections in the earlier data analysis. In this case the particular strategies of abstraction, subsumption, contextualisation and functionality were used.

The constructivist approach was used in further exploring and understanding the metaphors identified, it is linguistic and contextual, reflecting understanding of language and how it is located in the individuals' experience of their world. Thus, not only do metaphors have a rhetorical and symbolic function, they also have an epistemological function. This is informed by Lakoff & Johnson's (1980a) constructivist approach to metaphor which equally values both thought and language that together creatively construct the reality of the person's experience.

Major themes emerged, these were resonant with existing literature and were familiar to me from clinical practice when thinking about diseases such as cancer and heart disease. The metaphors used by groups and societies are often culturally influenced, thus for the physician groups participating in this study there is likely to be a shared language and understanding. As a fellow professional (although not a doctor) my knowledge base was partially helpful in sensitising me to identifying both overt and covert metaphors.

In this study, it is medical consultants' personal and professional experiences of the factors influencing end of life care referral practices that are considered. Their use of language provided data to elicit their individual and shared understanding and enable exploration of their emotions and emotional work (Lakoff & Johnson 1980b; Froggatt 1998). Not all of the participants' use of language and metaphor was enlightening, for Ben language appeared rudimentary and was used to provide a largely factual account of issues in practice.

There was a difference in the use of language and metaphor between the three participant groups. The cardiologists were more factual and matter-of-fact in their accounts, the oncologists appeared to bring more emotional language to their experiences and the old age psychiatrists appeared to use hidden metaphors that were initially more difficult to discern.

#### **11.4.1 The cardiologists.**

The use of shared metaphors was apparent for the cardiologists as a group, in that they were more pragmatic, more technical and less rhetorical. The concept of root metaphors fits with this participant group, the primary root metaphor relates to the mechanistic concept of universe being a machine whereby the body is seen as a container and the emotions are the energy or fluid in the container. The cardiologists' choice of words linked to historical perception of the body being seen as a machine, the heart being the pump or engine and cardiologists being primarily concerned with the technical aspects of patient management. Heart failure implies that the 'heart is going to stop or give up'.

As a group they all talked more about 'management' as opposed to 'care'. Their therapeutic perspective supports the idea that cardiac disease involves a problem or a failure that is mechanical, there is no shame attached to this unlike the 'taboos' associated historically with people suffering from TB and cancer (Sontag 1989). This taboo still pervades the experience of cancer.

The idea of this mechanistic approach may not be helpful in that it implies that the heart is divorced from the rest of the body and hence the emotions. It is clear when looking at the physiological consequences of heart failure that it has a secondary impact on other body systems. Cause and effect such as left heart failure leading to breathlessness on exertion and fatigue and right heart failure causing consequent fluid retention and oedema especially of the lower limbs and anorexia. This is resonant with the engine that needs other components to enable the car to move. Thus there is a holistic element to heart disease that it is linked to physiological processes, but the heart is also just a complex machine.

People with heart failure appear 'done to' and repaired, being more passive recipients of interventions. Ben describes his approach:

We see people who are breathless and look at it from a cardio-vascular perspective to try and get rid of fluid and vasodilate and deal with the issues that are causing the

breathlessness rather than dealing with the symptoms (Ben).

For me this seems comparable to a car mechanic suggesting an oil and filter change to ease pressure on the engine. He describes a clear cut goal of getting the patient better and of the patient being completely focussed on that and wanting 'to carry on living for as long as possible'.

Outpatient visits and management being perhaps analogous to the annual car service with particular maintenance aspects determining disease stability or progression. Ben describes a pragmatic approach to service delivery whereby patients receive a

20 minute consultation every three to six months in outpatients and we don't really have time to go into the detail of the patients feelings about their treatment or where they see things going. It's very much a how are you? How are you doing? What's your weight doing? Let's see your kidney tests, what tablets you're taking. Do this, do that and have these tests done, every month for the next six months and we'll see you in six months time if there's no problem.

Further probing elicited the following response:

Yes it's not holistic care because there is no time for holistic care when you haven't got facilities to provide [even] the basic service (Ben).

Alex talks about the 'fine tuning of treatment' that with the use of medical and device therapy there is always the possibility of introducing something new that might help. He reflects that this approach denies the possibility of palliation, as a cardiologist he suffers from 'tunnel vision' and fails to think more holistically. He describes palliative care as a sort of rather depressive outcome to their management and implies that it may have a damaging psychological impact on patients.

Ultimately mechanical failure leads to potential car scrappage. Alex talks about when the patient is at the 'end of the road' there is almost a sort of pulling back, not an active pulling back but a sort of passive pulling back of involvement and therapies prior to referral. With disease progression, Ben

identifies that there is an uncertainty as to whether we should be heading in the direction of active interventions. Chris concurs stating that when it was clear that the patient was going to die with end stage heart failure for which it had earlier been established there was no further intervention that was going to alter that direction of travel then we asked the palliative care to come in. For all identifying the 'tipping point' between active and palliative care was characterised by much uncertainty, due to the unpredictable disease trajectory associated with heart failure.

For most cardiology patients referral is not indicated as they are able to deal with their exacerbations and restore them to 'functionality' in their community, Chris describes this as being when we can actually turn things around, reverse the downhill journey. Dan, again using mechanical metaphor, describes the myriad of therapies available in cardiology that can make people better as being great and a positive element of his experience but you have to accept there are times when you cannot make somebody better. It is important to acknowledge when the end of the journey is reached, that the use of the end of life care pathway is appropriate as a way of signposting a change of route in care. Referral to palliative care is described as 'changing gear'.

The metaphors linked to car mechanics appear gender specific that is masculine, which reflects the gender dominance of cardiologists in the UK (British Cardiovascular Society working group 2006) and is reinforced by all the cardiology participants being men. The metaphors of tunnel vision, changing gear and direction appear to move the mechanical images associated with cardiology further towards the idea of a journey. Dan describes many of his heart failure patients as having no reserves, and that one 'extra insult that tips them over the top very quickly'. However despite this, in supporting the uncertainty of the journey, he also describes clinical situations where patients bounce back and they 'perk up a treat when you withdraw the treatments, they rally'. The phrase 'perk up' links with engine tuning which aims to revitalise the engine.

This contemporary view of a patient's journey, the person's experience of living with chronic disease, is based on the premise (described in much literature) that the quality of people's lives is at least as important to them as the length of their lives. Their journey is characterised by uncertainty, patients need for clinicians as companions, providers of information, help and treatment; or as in this thesis, professionals facilitating and negotiating their transition from active to palliative care (Sontag 1978, Kleinman 1988; Greenhalgh & Hurwitz 1999; Lapsley 2004).

In relation to clinical transitions from interventional treatment to palliative care the cardiologists' accounts were characterised by binary oppositions in language from activity and passivity, from light and dark. Their understanding of palliative care was shaped by their shared culture, the binary opposites [pairs] used provided evidence of their mutual understanding. Their valuing of the 'high tech' approach in cardiology is contrasted with their perception of palliative care as being more 'low-tech' in approach. Their choice of words supports Derrida's idea that binary pairs are never equal that one side of the binary pair is more highly valued. He suggests that these pairings are highly judgemental and support 'cultural stereotypes' (Derrida 1973). This supports the cardiologists' rather ambivalent, almost dismissive, perceptions of palliative care as being a passive approach to care.

For the cardiologists, language and metaphor suggests a real tension between the humanising and technical aspects of their role. They have quite long term relationships with those in their care and in their descriptions of adjusting to their patients decline, their language becomes more reflective and emotional.

Three of the cardiologists talked, from a theoretical perspective, about the important role of heart failure nurse specialists in filling the gap between the aggressive cardiological approach and the palliative approach. Ben, Alex and Chris indicate that nurses could be the 'bridge' between the two specialities and between primary, secondary and tertiary care providing a seamless link. Dan, working currently with heart failure nurses as part of his core team,

acknowledges their value but highlights the practical workload dilemma for them in providing care to those at diagnosis, during treatment and at the end of life, they are 'spread very thin'. He suggests a regionally based nurse who is skilled in both palliative and heart failure care as offering a 'troubleshooting' type service, whereby they 'dip in and pull out' dependent on actual need, a bit like the Automobile Association.

#### **11.4.2 The oncologists.**

The oncologists as a group were generally more verbose and fulsome in their answers, their interviews on average lasting longer than those of the other groups. Their use of language was more emotive and varied, I initially thought this to be present only in the interviews with Eve and Hermione and therefore gender related but the interview with Greg proved this not to be the case. As discussed before, Greg's interview was the least structured, the longest and displayed more feeling and emotion.

The metaphors and analogies used by the oncologists were predominantly associated with war, the war on cancer. I was unsure whether these were derived from their own experience or whether they drew on metaphors that were already familiar to them. Particularly as military metaphors associated with cancer have been well recognised in historical and philosophical literature; describing a fight or crusade against cancer, that it is a killer disease whereby people with cancer are seen as victims (Sontag 1978; Hodgkin 1985; Penson et al 2004). Flynn acknowledges that 'we're dealing with history in cancer management all the time'.

The idea of battling against disease may or may not be helpful as for some patients there is the element of fighting at all costs, the role of oncologists being to provide the ammunition. Typical newspaper obituaries reflect this approach 'died after a long battle bravely borne', 'lost the battle after a long, courageous fight' or 'at peace at last' (Penarth Times; Daily Telegraph).

Sontag (1989:99) from her experience as a cancer patient describes the 'metaphoric trappings that deform the experience of having cancer'. To



elucidate, the metaphors used by the oncologists and also present in Sontag's experience, seem to cast their consultant role as being commanders or soldiers; treatments as the weapons; the disease, cancer, as the enemy; with patients being the casualties of war, victims or survivors. The progression of cancer perhaps relates to the enemy bringing in reinforcements. The public and media perception seems to focus cancer research as searching for the 'magic bullet'. The oncologists' use of military metaphors implies that they are concentrating on the more physical elements of cancer care, the patient appears passive or the site of conflict with the oncologist being active and in control.

The transition to palliative care may be seen not as a 'ceasefire' rather more of a retreat or in some cases earlier referral being a 'safety net'. This unique metaphor was individually mentioned by all the oncologists. It was used in relation to explicating the advantages of palliative care, this for me conjured up images of being caught when falling or trying something new, perhaps in relation to acrobatics in a circus. The safety net appeared to have a dual purpose acting as a support both for them as professionals and for their patient group. For Hermione, this safety net makes her life easier and smoothes the waters for patients acting as a 'go between' in accessing help and support.

Hermione uses a unique contemporary metaphor in likening the role of palliative care services as being akin to 'Ghostbusters', this was a 1984 science fiction film about three eccentric parapsychologists, (ghost-capturers) who were hired to find and eliminate demonic ghosts that wreak havoc in individuals' lives. The analogy to cancer perhaps relates to its hidden presence, its unpredictable behaviour and its malign, all encompassing impact on people's lives. Thus palliative care appears to be a point of help and contact for those 'experiencing the panic', 'Ghostbusters' being equivalent to the safety net of palliative care.

For Flynn, this safety net was there to support advanced or anticipatory care planning at the 'crunch point' a terminal decline, palliative care providing

'reserve back up' and a 'contingency plan' continuing the military imagery. He described 'red flags' symbolising a warning leading to a 'sudden shift or change in outlook', there was however no mention of white flags relating to surrender or cease fire. For him, the safety net is there to support patients when 'the cracks come' in the family's ability to cope or to the patients unique social situation, that may relate to age (very old or very young) or social support.

Greg has a different perspective on the 'safety net', he describes doing a joint ward round with a palliative care consultant which enabled identification of palliative patients 'who could be brought back [*to the oncology unit*] for active treatment'. This related to GP's referring patients prematurely to palliative care whereby some patients may miss out on active treatments. This might link with premature surrender. Hermione describes many people 'who resist palliative care all the way'; or 'just won't really engage'; this suggests an element of denial or continued active fighting, that palliative care is seen as a defeat or as surrender to superior forces.

Cancer care described by Eve, Flynn, Greg and Hermione is a very active, interventionist speciality, this is evidenced by their choice of language. Eve states that many people accept the diagnosis and move on to considering the battle, specifically asking about the active treatment interventions, usually cytotoxic chemotherapy

Greg stated that in his experience palliative care was treated with some suspicion, in that it had 'grown like Topsy'. This is an interesting metaphor that has passed into common usage with the specific meaning of unplanned growth, sometimes just meaning enormous growth. The idea of unplanned, erratic growth is also consistent with the mental imagery of the growth of a cancer. The privileging of palliative care at strategic level and its development to non-cancer conditions also supports the Topsy metaphor, in that its outcomes have not been well evaluated.

Greg's personal, historical perspective in describing some palliative care consultants as 'empire builders' with their approach to the development of palliative care being akin to invaders of a country that was previously the realm of oncologists. Other oncologists' metaphors limitedly supported this historical approach but more contemporary thoughts are emerging suggesting that cancer and palliative care are fighting together, perhaps this is where the idea of the safety net emerges.

Consistent with Sontag's description (1978), metaphors associated with travelling or journeys are limitedly present in the oncologists' stories (compared with the cardiologists). Hermione describes the association of the word hospice and a morphine prescription being the last resort, the end of the road now. Eve illustrates this with the journey idea of being 'shipped off to a hospice'. Flynn reflects that for some patients a palliative care referral is a one-way ticket. This is congruent with much of the literature on the patient's journey, the most common disease exemplar being cancer (NAO 2005). Most personal journey narratives are characterised by the patient either being a coward (Diamond 1999) or brave, fighting a battle against overwhelming odds (Picardie 1998). These perspectives link back to military metaphors.

The process of dying from advanced cancer is described by many of the oncologists as being 'hard work'. Some people live or barely live with advanced cancer, the journey is quicker for those with lung cancer for example, than ovarian cancer or brain tumours and sometimes the journey is quite cruel, in that it is almost independently driven. This reflects a degree of powerlessness and difficulty associated with supporting people dying from advanced cancer. This was not universally acknowledged by the cardiology and old age psychiatry participants in this thesis who perceived a cancer death as being 'easier', especially in diagnosing the terminal phase and supporting the introduction of palliative care. Palliative care however gives people 'a chance to do things, write things, leave things' a sort of putting things in order, this links with military metaphors perhaps in keeping a documentary record of the battle akin to a documentary record of their lives and keeping themselves present in the lives of future generations.

In parts of the interviews the oncologists' language and tone used when describing palliative care appears softer. Eve specifically uses more allegorical, spiritual words such as a hospice offering an environment of care that enables people 'to get more peace' rather than 'languishing on the wards', or being on a 'chaotic oncology ward'. Flynn in contrast describes palliative care more actively in that it 'may have extra expertise or it may provide more intensive [*symptom*] management', the analogy linking perhaps with the use of re-enforcements.

In cancer and heart disease the use of analogy and metaphor may have a protective function, explicating a shared understanding. The cancer and heart failure patient in most cases remains sentient, capable of choice and decision making therefore being more of an active participant in the consequent journey or battle.

#### **11.4.3 Old age psychiatrists.**

The old age psychiatrists' interviews were characterised by less overt metaphors, although it was present, there was an element of fatalism and nihilism in their responses. Mair stated for example, that there are worse things than dying (although it is difficult to imagine in some respects something worse than dying) and her assertion that living and dying is in 'God's gift' which links closely with the literature associated with professional religiosity (Wenger & Carmel 2004; Seale 2010). Her choice of language appeared influenced by her faith and religious discourses.

It appears that the psychiatrists see themselves as more passive onlookers in their patients' journey compared with the more active interventions associated with oncology and cardiology. There is a pervasive element in their accounts which appears to separate the mind and body in the person with dementia. As the dementia progresses the individual becomes less sentient and has things done to them that are instigated and authorised by their family or professionals, their body is the object of care rather than the subject of care. Specific clinical examples relate to DNAR orders and the withholding and withdrawing of food and fluids. The view that the rational mind dominates and

is the essence of the person supports the idea that the body has a lower status when divorced from a rational mind, as in the case of Alzheimer's disease. As the disease progresses, the body's physical needs become increasingly dominant, Ian describes it as:

So all sense may have gone but the body is still going to operate for a significant length of time independently of any sense and therefore will need to be looked after (Ian).

This echoes philosophical and historical understandings of how the body and mind are perceived in Western society. Originating in the rational philosophy of Cartesian dualism where the split between the mind and body negates the holistic elements of individual being and their social world (Shand 2002). Dying may be less of a problem for old age psychiatrists as their patients may have already died a social death, they are no longer people for whom it is possible to have a relationship with and all that remains is the 'shell' (Sweeting & Gilhooly 1997; Brannelly 2011). This is familiar for those with progressive advanced dementia who experience social withdrawal and isolation, but more resonant for this group of patients is the idea of the 'body neglected' (Edwards 1998; Phinney & Chesla 2003).

The Cartesian mechanistic approach separates the mind and body, with a further separation being made between reason and emotion. In advanced cancer and heart failure individuals, mental and cognitive processes generally remain intact (until the last days of life) and as a consequence they are still more active participants in their care.

The end of life event for people with dementia is characterised by passive language and metaphor, Ian, reflecting, states that he sometimes uses the word terminal and sometimes uses the phrase mother-nature. For Mair 'we get patients that just simply die of their dementia'. There feels a gentle rather natural process at work in their descriptions, that it is nothing dramatic rather there is a degree of inevitability or predictability about it.

The perceived emotional burden of caring apparent in some nursing literature appears only to resonate with Ian and Mair's experience of managing patients with suicidal ideation, it did not appear to impact on their experiences in caring for dementia patients at the end of life. Deaths following suicide appear to have a more personal negative impact, with associations of them being blamed and in some way responsible. This was exemplified by the subsequent investigations and media attention that both saw as apportioning blame. Deaths from suicide have a particular contemporary relevance in the geographical area they both work and link to the increasing prevalence of suicide in the older population, although the rate for both sexes decreases above the age of 75 (ONS 2010).

Mair, when talking about complaints, recognises that care for those in the last days of their lives is, for her, the least stressful professional activity. For Ian, more of his interview focussed on complaints, litigation and investigations that often followed a suicide:

The style of the investigation was to take all the staff and take them individually into a room with a spotlight: what did you do, what didn't you do, why did you do that and why didn't your friend do that and to be fair the ward team should have disintegrated but they didn't they held together and they you know were all stronger for the experience but I thought it was appalling (Ian).

His choice of language in this narrative supports what feels a very inquisitorial and adversarial process, elements of the language suggest an analogy with prisoners being tortured. For Ian, this experience was one that felt damaging to him and the team. He sees himself as almost the protector of his staff and as a negotiator in trying to achieve a less interrogative approach.

Historical perspectives of mental illness identify it as having some positive consequences. As Sontag (1989:109) describes:

In the twentieth century there was a persistent fantasy about mental illness as a source of artistic creativity or spiritual originality.

This is evidenced for example by the lives of Van Gogh romanticised by Don Maclean in the song 'Vincent' (1971) or Sylvia Plath's semi-autobiographical account of her decline into mental illness in 'The Bell Jar' (2005). This approach does not equate with the personal experience of dementia which generally occurs in later life and is characterised by progressive mental decline that leads to increasing dependence. For the person with advanced dementia they may not need the protection of analogy and metaphor, as the disease progresses its impact on the individual is depersonalising. It is perhaps that the patient exists in parallel universe with the family and professionals left behind in the real world.

There is increasing awareness that inherited genetic factors are responsible for the development of certain diseases, such as those being explored in this thesis; cancer, heart disease, Alzheimer's disease and dementia, this may have a future impact on the use of analogy and metaphor. Historically certain diseases, predominantly those genetically linked, have been associated with the idea of 'bad blood'. There was no evidence of this influencing the consultants' experience or use of language.

The issues of disease causality might have had an impact on the consultants' use of metaphor. Heart disease and cancer appear in part to be related to external factors, the things we do to our bodies. For cancer, smoking, diet, alcohol, sun exposure and viruses are all implicated; for heart disease it is again smoking, diet and alcohol together with obesity and a sedentary lifestyle, together with concurrent illnesses in particular diabetes and hypertension. Causality is less clear in dementia, inherited factors are implicated but most dementias appear linked to longevity and declining of mental processes. Psychosocial factors also appear to contribute but the evidence is equivocal. Again issues of causality were not present in most of the consultants' stories except for Hermione who linked smoking and cancer.

## **11.5 CONCLUSION**

Alvesson (2010) describes and supports the concentration of language and metaphor in this chapter which has encouraged:

a re-conceptualisation of the interview which involves theoretical abstraction and the use of a vocabulary that also encourages an openness to complex patterns and depth thinking, thus moving beyond a view of interviews as the optimisation of techniques and the minimisation of bias.

Much medical language is constructed around a few metaphors, there is a consistency between the language of my participants and that appearing in the literature related to the practice of medicine is war. The participants' use of language as described in this chapter provided a greater insight and understanding of the more personal complexities of their experience and their life-world of practice.

Chapters 9, 10 and 11, the discussion chapters, have together attempted to broaden understanding of the consultants' experiences by shedding light on the complex factors involved in the care of the people at the end of life.

The next chapter will explore the consider issues of quality and the role of the researcher in the development of this thesis.



## **CHAPTER 12 - VALIDITY AND QUALITY ISSUES, TOGETHER WITH REFLECTIONS ON THE RESEARCH JOURNEY.**

**[Quality] requires a much more active and labour-intensive approach towards genuinely self-critical research, so that something of originality and value is created, with which, of course, people are then always free to disagree, but may be less inclined to do so because of the strength of the author's case. (Seale 1999:6).**

### **12.1 INTRODUCTION**

Demonstrating validity and quality in qualitative research is about making a judgement as to how well the research has been carried out and to what extent the findings can be considered trustworthy and useful (Yardley cited in Smith 2008). Consistent with the philosophical and methodological requirements of IPA this chapter will initially explore the role of the researcher, specifically considering the concepts of reflexivity and openness. Then in section 12.3, it will consider validity and quality using Yardley's guidelines and four principles as a framework (Yardley 2000). The privileging of Yardley's work is consistent with Smith et al's (2009) recommendations for assessing quality in IPA. The chapter will conclude with personal reflection on the IPA research process and experience.

### **12.2 REFLEXIVITY**

Phenomenological methods focus on deriving rich and detailed descriptions of lived experience and meanings. For example, Husserl's technique of phenomenological reduction by bracketing (the rejection of presupposition and the concentration being the phenomenon as the primary reality) and Giorgi's empirical phenomenology (which tries to establish the essential features and general structure of experience across people) focus on lived experience. Both approaches try to minimise the influence of the researcher (Giorgi & Giorgi cited in Smith 2008).

In contrast IPA's idiographic and inductive method, which seeks to explore participants' personal lived experiences, is phenomenological in its concern for individuals' perceptions. In praxis it identifies more strongly with

hermeneutic traditions which recognise and support the central role played by interpretation and the researcher. Smith (2008) does not advocate the use of bracketing, believing that it is not possible to achieve a value free understanding of the participant's world. He believes the participants' experience is complicated by the researcher's preconceptions but these preconceptions are valuable and an essential requirement of IPA. These preconceptions support the reciprocal interpretive activity required in order to make sense of the other person's world.

Historically reflexivity has been understood as a turning back of one's experience upon oneself (Steier 1991). It may lessen but not negate preconceptions held by the researcher; some biases might remain as they may be unconscious or subliminal. All phenomenologists accept that researcher subjectivity is implicated in research. It is this interconnectedness between researcher and researched that characterises phenomenology (Finlay 2008). The difference as to how and to what extent the researcher is present inform the chosen phenomenological approach as described in Chapter 4.

Interpretive forms of phenomenology, outlined by Gadamer and Heidegger, argue that the knowledge of the researcher, when acknowledged, may enable and support greater understanding. Colaizzi (1973) acknowledges the importance of self reflection as part of the research process, enabling the researcher's preconceptions, biases and suppositions to be made apparent and therefore divorced from the participants' stories and descriptions. This is summarised by Gadamer (1997) as being open to the other whilst recognising biases throughout the research journey. Linking with the earlier ideas of knowing presented in this thesis and acknowledging the influence of Gadamer, Finlay concludes that 'knowledge in the human sciences always involves some self-knowledge' (2009:12).

Finlay (2009) also describes the tension between bracketing pre-understandings and exploiting them as a source of insight, IPA's approach values the latter. Therefore, what is unique in IPA is the central role of the

researcher in helping the participant to achieve understanding of their unique experience. Practically Finlay suggests the researcher should adopt a recursive approach focussing on personal assumptions and returning to look at the participants' experiences in a fresh way (Finlay 2008, 2009). In more recent IPA research, as in this thesis, it also seeks to elicit the shared understanding within groups and comparatively across groups. It values the experiences of the researcher in supporting and explicating understanding of experience, in searching for patterns, connections and tensions (Murray & Chamberlain 1999). There is clearly a danger in that the research becomes all about the researcher. Smith et al (2009) outlined measures to maintain and preserve the participants' version of their experience. The use of specific techniques for establishing patterns and connections in this thesis has been supported in the text by verbatim quotes to ensure the presence of each participant's voice.

The challenge in qualitative research, from a post-positivist perspective is to achieve a level of participation in research that is not distant nor completely personal. IPA supports the approach of a more involved researcher but also recognises the delicate balance between detachment and attachment with the participants, world and experience (Shaw 2010). Greg's description of a professional encounter (presented in Chapter 10 as a 'little gem') which shaped his subsequent career illustrates the inherent reflexivity (associated with IPA) in the research interview. It supported a way of navigating through his story by encouraging a deeper level of disclosure, enhancing Greg's own understanding of this experience and its influence on his professional life. Greg stated he had never before told the whole story of this incident. This encouraged me to question him more deeply and to share with him how certain clinical colleagues were influential in shaping my professional role. The theoretical worth of IPA lies in its way of presenting new ways to explore and understand a topic. This was evident by my comfort and flexibility during the interviews. Gadamer (1997) describes this as openness, being a wish to see and to understand something in a new way, rather than reflexivity.

The steps in IPA analysis have provided a systematic way of dealing with the interview data but the use of the hermeneutic circle and questions guiding the analysis attempted to ensure a more holistic and open approach. The attitude adopted by listening to and hearing the participants' stories, demonstrated my openness to the subject and to the participant (Pringle et al 2011). The participants' description of the more personal aspects of their experience, their willingness to engage with sensitive and difficult subjects suggests their openness.

### **12.3 OPENNESS.**

This section will explore the issue of openness in the context of this thesis, it will be supported by examples of my reflections on the research process. Openness in this instance, as described by Yardley is supported by four interrelated dimensions: openness to the research situation, the research subject or question, to the participants and to oneself (Yardley 2000, 2008).

Firstly, it is an obligation for the researcher to ensure, by whatever means, that the participant's experience is revealed to the greatest extent possible. In this thesis an open, unstructured and facilitative questioning approach to data collection in the interviews tried to establish a reciprocal relationship, this was supported by self disclosure at the time of recruitment in which they were aware of my clinical experience in palliative care and my nursing and academic background. Probes and prompts were used to achieve a greater understanding. There were a few times, with a degree of caution, when I shared my own clinical and personal experiences, these were especially related to my father's final illness.

Secondly, the choice of research question and the approach in undertaking the research indicates a degree of openness. This was supported by an eclectic approach in reviewing relevant but also wide-ranging literature. The first part of this thesis describes the literature review processes undertaken in support of contextualising the study from structural and theoretical perspectives. The necessary element of methodological openness was supported by using the approaches of IPA and reflective life-world philosophy

as a way of exploring my participants' experiences from many perspectives. This ensured that I was present and as fully immersed as possible in the participant's experience in order to remain focussed.

The participant's openness was assured by acknowledgement of the value of their individual experience and the assured confidentiality associated with their participation. The veracity of their experience was not the prime concern; I was aware that truth is a subjective reality that is likely to be experienced differently by each individual participant and their described experiences being accounts of past events that in their remembering may have been reconstructed. The power balance between the consultants and myself appeared equal. The selected consultants were 'experts' in their clinical and professional sphere and in what they chose to disclose of their experiences and their life-world. On reflection I was perhaps the 'expert' in initiating, controlling and benefiting from the research and their participation.

Finally, the idea of 'self-openness' which relates to my contribution to the research in relation to personality, style and the degree of emotional involvement in the thesis which, in this case, is considerable as the topic for exploration was chosen by me having both personal and professional motivation for that choice.

Earlier, from a sociological perspective, Smaling (1995) took a subtly different stance in describing the role openness could and should take in health and social care research. He describes three kinds of openness: open-mindedness, open-heartedness and dialogical openness. Open-mindedness refers to the receptivity of the researcher to the participants and the subject of the thesis. This approach is congruent with the values of IPA and for me is enabled by my professional role which enabled a more informed, equitable and active listening dialogue as part of the data collection process, an inter-subjective relationship being present (Wood & Ross-Kerr 2006). It also supports Heidegger's interpretative concept of 'being with' and the notion of 'goal free listening': in the case of this thesis it is about being with the participant, their life-world, their experience and the data. Smith et al (2009)

describe this as having total immersion in and with the research process and the interview data, establishing a close, open research relationship. This is evidenced by my familiarity with the content of the interviews and thus the participants' experience.

The second kind of openness Smaling (1995) describes is open-heartedness, this relates to a self revelatory or self disclosing attitude and approach especially in the interviews. This involved sharing my professional background (nursing) and specialist knowledge base (palliative and end of life care) in which I was known by reputation to most of the participants in advance of the interviews. It also involved sharing the personal experience of my father's life-threatening illness which was very present during the interviews with the cardiologists and the oncologists, and his subsequent death which occurred prior to the interviews with the old age psychiatrists. I am unable to determine how this impacted on the interviews and remain equivocal as to whether it acted as a barrier or an enabler. On reflection I believe self disclosure in most instances made the participants more comfortable and relaxed in talking about their own experiences. This was evidenced by Greg and Flynn sharing with me information that they had not disclosed beyond their immediate family.

A key aspect of quality is demonstrating critical reflexivity on the part of the researcher. I have questioned whether my disclosures may have influenced the direction of travel of the interviews, a methodological consequence. Together with whether what was revealed in their interviews was their experience or a corroboration of my experience, which would be a more ethical concern. Analysis of the interview transcripts and my field notes confirm that my self disclosure was contingent on related discussion or disclosure by the participants. For example, it was only when Mair described the death of her father that I disclosed that my father had died a few weeks earlier. Hermione's description of her grand-father's dying trajectory and experience was followed by my personal comment that it was often more difficult to watch and be powerless to make the experience of loved ones better.

From the life-world perspective, how did I, as someone who shared elements of their life-world, use this to influence or constitute my interpretation of their experiences? This open-heartedness, prospective, open and reflective awareness may have militated against it, influencing the experience of my participants but it is difficult to be sure about this.

Smaling's (1995) third exemplar of openness refers to a dialogical openness with other researchers, in my case this occurred with my supervisors as a means of challenge, ensuring objectivity and enabling me to consider new perspectives in looking at the data. He also describes this as including further conversations with the participants, within the constraints of this research this has not occurred although all did agree to further contact if necessary and wished to be informed when it was complete and what was discovered. Supporting openness they all agreed in the consent process to verbatim quotes being used in the thesis and any subsequent publications and were assured of anonymity.

The above descriptions of openness are thought to reflect an element of quality in qualitative research (Yardley 2000). Other aspects of quality will be explored in the next section.

## **12.4 DIMENSIONS OF QUALITY**

Smith et al (2009) suggest the methods employed in any IPA study should be considered and assessed for validity using Yardley's guidelines, her four principles for assessing the worth of qualitative research (Yardley 2000) and in particular IPA research are outlined below (Yardley 2008 cited in Smith 2008).

- **'Sensitivity to context'**  
*Theoretical; relevant literature; empirical data; socio-cultural setting; the participants' perspectives; ethical issues.*
- **Commitment and rigour**  
*In-depth engagement with topic; methodological competence/skill; thorough data collection; depth/breadth of analysis.*
- **Transparency and coherence**  
*Clarity and power of description/argument; transparent methods and data presentation; fit between theory and method; reflexivity.*
- **Impact and importance**

*Theoretical (enriching understanding); socio-cultural; practical (for community, policy makers and health workers).*

The essential qualities are shown in bold with examples of the form each can take shown in italics' (Yardley 2000:219).

For this thesis, Yardley's guidelines and principles have been chosen as they appear simple to follow, flexible and comprehensive. I will describe elements of my thesis with each of Yardley's principles in turn, demonstrating the validity of the approach adopted and linking it together with a description of the distinctive features of IPA, ensuring the core concerns are recognisable and central in the thesis. There will, by necessity and congruent with qualitative approaches, be a flexible interpretation of these principles.

#### **12.4.1 Sensitivity to context**

Sensitivity to context was demonstrated by the wide-ranging literature review which focussed on the structural contexts of health care organisation and palliative care and the theoretical contexts underpinning the consultants' clinical practice. Consistent with IPA it privileged the personal, idiographic experience of each consultant and helped them achieve an understanding of their unique experience in their life-world by the use of open-ended and unstructured interviews.

IPA being a micro-level theory, (Reeves et al 2008) explores specific phenomena and the contexts of care but is supported by a wider structural and theoretical understanding. Thus this thesis attempts to consider the vertical generalisations in the discussion chapters by attempting to link their particular experience to the abstract and the work of others as outlined in Chapters 9 and 10 (Johnson cited by Yardley 2000; Polkinghorne 2005, 2006).

In this thesis the sensitivity to the importance of the consultants' use of language was crucial in interpreting its meaning and function. It illuminated critical elements of their experience and made them more accessible, enabling a more complete interpretation and understanding.



#### **12.4.2 Commitment and rigour**

As a neophyte researcher the clear cut procedures outlined by IPA may achieve a methodological soundness but do not necessarily provide evidence of quality. My commitment was demonstrated by the care shown to my participants in the interviews; they were a small number specifically chosen for their special attributes and experiences. The open-ended questions and minimally structured approach attempted to show each of the consultants respect and inculcate the interviews with a valuing of their unique perspective. Their willingness to participate, to answer both professional and personal questions, with two of the participants sharing experiences that they had not previously described in depth before, supports my commitment, sensitivity and transparency.

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Rigour is made apparent by the clear trail (see Chapters 5, 6, 7, 8 and 11) that explains the processes involved in the interviews together with the thorough and systematic descriptive, linguistic and conceptual analysis which demonstrates methodological skill and practical competence. Thoroughness of this thesis was also demonstrated by the choice of medical consultants, the study sample selected being the specific group identified in the research question and being the 'gatekeepers' in enabling or hindering access to SPCS.

The analysis was interpretative in that it moved beyond description to eliciting meanings and understandings. Identification of individual and shared themes was supported by the use of verbatim quotes.

#### **12.4.3 Transparency and coherence**

Reflexive skills, as part of the concept of transparency, enable the combining of these apparently opposing elements of the consultants' stories to form a gestalt of the experience. IPA indicates that this can be demonstrated by the important check of relating the identified themes back to the original verbatim transcripts. In this thesis it was supported by the constant reading and re-reading of the transcripts before during and after data analysis. Equally helpful for me was that throughout the research journey I regularly re-listened

to the interviews with the consultants. I remained constantly immersed and engaged with their stories, they became very familiar to me and their individual voice was consistently heard as well as supporting understanding of their shared experience.

This constant involvement also supported the multilayered interpretative activity associated with IPA that requires equipoise between a hermeneutics of empathy and a hermeneutics of suspicion (Smith et al 2009) but for me felt more like a hermeneutics of curiosity. This multilayered approach to interpretation contributed to what IPA describes as a 'good enough' analysis.

Smith et al (2009) believe that Yardley outlines two possible elements to demonstrate coherence. Firstly by making clear that there is a fit between the research undertaken and the principles of IPA and secondly that there is consistency in the arguments made when the themes are identified, in their interpretation and in the writing up of the thesis. The writing up of the thesis provided a nuanced account of convergence, divergence and of the consultants' unique and shared experience.

The fit between the research question and aims and the research approach of IPA evolved together with my understanding of what I was hoping to achieve. I was hoping to achieve more than a description of their clinical lived experience, the aim was to explore and understand the factors influencing their referral practices (or not) to SPCS. This required a deeper understanding of the structural contexts (such as clinical and professional) and the ability to link aspects of their practice to more theoretical contexts (such as knowing and the life-world). The structural and theoretical contexts were apparent throughout the research journey. For example the macro, meso and micro structural levels of health care together with dimensions of knowing impact on the consultants decision making in practice. Thus IPA's methodological and philosophical approach enabled exploration of the meaning of their experiences through interpretation and discussion.

#### **12.4.4 Impact and importance**

This element of quality is demonstrated by how well the research was undertaken and how interesting, important and potentially useful their experiences proved to be. The experience described by the consultants demonstrated links with theoretical perspectives, the influences of the life world, habitus and their individual personal and social histories. The importance of social constructionist epistemology, that informs IPA, is that individual meanings are not primarily constructed by the experience of the individual person. Instead they are socially constructed and come into being in and out of human interaction, describing the aspects that make up experience. Ways, possibilities and constraints inherent in the material world shape and inform the social constructions we live through and with. As Cromby & Nightingale (1999) identify, the structural features of society, including its inequalities, the power of institutions and governments and the organisation of health care all have an impact on research. In this thesis these impact on the consultants' experience and helped shape and inform their understanding.

#### **12.4.5 Conclusion**

As described earlier in Chapter 4, this thesis fits with the requirements of the IPA approach in that it concentrates on specific individuals (medical consultants) as they deal with the specific situation of end of life care and the involvement of SPCS for their patient group. It considers their personal and professional perspectives and experiences. The interview account is built by the participant and the researcher, co-constituted and influenced by the life-world.

During the interviews physicians were asked to reflect on and explore their process of decision-making rather than on its outcome, considering the factors and meanings that influence their course of action or inaction. (Smith et al 2009). Its focus relates to significant issues, either ongoing or at a critical juncture in life, that inform and enable detailed exploration of factors influencing consultants to refer or not refer their patients to SPCS, it concentrates on the particular rather than the universal experience.

The study uses IPA to examine these factors in an attempt to make sense of their impact on the individuals decision-making. The detail of the idiographic case enables the researcher to get closer to how participants make sense of their experiences. Little is known about why physicians refer or do not refer, it is about understanding processes not measuring outcomes and is concerned with experiences, feelings and attitudes. It explores the individual experience, supports clinical heuristics, and enables the value of difference. IPA's philosophical underpinnings appear congruent with end of life care.

## **12.5 REFLECTIONS**

### **12.5.1 Methodological**

The following section presents my reflections on the use of IPA and the research journey. The benefits for me as a neophyte researcher, as alluded to earlier, relate to IPA's user-friendly approach which is in direct contrast to many other qualitative methodologies. The clear-cut guidelines and accessible language make for ease of understanding and application. This flexible and inductive approach proved especially useful in exploring the participants' experience in seeking to understand difficult health care decisions, especially the individual, social and personal processes that influenced them.

The different levels of interpretation combine the hermeneutics of identity and empathy together with the hermeneutics of questioning, curiosity and being critical. Understanding is achieved by combining these creatively, Reid et al (2005) recognise the creative value of both using existing theoretical frameworks and engaging with new ideas and thoughts. This links with IPA's philosophical foundations in which Heidegger and Gadamer suggest fore-understanding is important in interpretation. Sometimes interpretation is enhanced by discovering something new. For me this was the consultants' use of language and metaphor which encouraged me to undertake linguistic analysis. This enabled me to discover new concepts such as binary opposites and derive fresh understandings that added to the understanding of their experience.

However IPA's approach was not 'methodolatory', it was enhanced and adapted in this thesis by the inclusion of the reflective life-world perspective. The rationale for combining these two approaches resonates with the justification proposed by Johnson et al (2004) who combined aspects of IPA and Foucauldian discourse analysis. Their argument was pragmatic and based on the idea that 'the choice of approach should be based on the goals of the research' (p.364). For me the choice of approach was not only based on the *goals* of the research but was influenced by the *need* to reflect and understand the consultants' experiences as fully as possible. This feels entirely congruent with the principles of IPA as outlined by Smith et al (2009).

Undertaking a preliminary literature review at the outset was helpful in providing a sound awareness of existing literature and the contemporary issues in end of life care. It enabled identification of potential gaps and uncertainties which proved helpful in preparing the proposal, identifying the research questions and the broad areas for exploration in the interviews. It is possible that this *a priori* knowledge may have subconsciously impacted on or influenced the data analysis, especially the identification of themes related to the structural aspects of palliative care. The multiple layers of interpretation supported the identification of unique themes which were only subsequently linked to other existing theoretical perspectives, for example 'habitus' and clinical mindlines. This necessitated substantial reworking of the literature review and its subsequent division into the structural context of specialist palliative care and the theoretical context of clinical thinking and knowing.

#### **12.5.2 Personal**

In presenting the findings from this study I am aware that I have made judgements. The processes by which these judgements have been derived rely on trustworthiness and a caring approach to the participants' narrative. This is demonstrated by my monitoring and reporting of the analytical procedures and processes as fully and truthfully as possible. Also being guided by the 'epistemic virtues' of IPA, in particular the use of the hermeneutic circle which supported the descriptive, conceptual and linguistic analysis (Patton 2002; Polkinghorne 2006; Smith et al 2009).

Mauthner & Doucet (2003) reflecting on their doctoral experiences suggest that reflexivity is limitedly possible at the time of doing research; influences can be more clearly observed following a period of distancing. Their account led me to suspect that my research has been externally influenced at all stages of the research journey. For this thesis the choices made in relation to the research methods and theoretical perspectives were perhaps influenced by my personal and professional biography, (as outlined in the preface to the thesis) as was the choice of literature and texts to guide the exploration. It is possible that this led me to privilege particular ways of 'seeing' and 'hearing' during the process of data analysis.

The possibility of showing partiality was a particular challenge when moving from the descriptive to the interpretative level of analysis. This interpretative process was characterised by many false starts or roads leading nowhere. Initially the interpretation focussed on the clinical and structural aspects of their experience but this did not reflect the more personal and contextual elements. Choosing to link the consultants experience to theoretical concepts such as the life-world was not the only possible route to deepen analysis. It was a useful and personally challenging way of encouraging a fresh perspective to achieving understanding.

The insider outsider perspectives impacted on my interpretation. Minimally I am an insider, I am not a physician, not male and clinical care is no longer my primary professional focus. However, I am an insider in relation to the fact that I am exploring issues related to my area of expertise, this is both a help and a hindrance in that it may enable or obscure understanding. The belief that I shared a common understanding of palliative care with the participants was not made explicit; in the early interviews I accepted their comments about traditional palliative care at face value without establishing their true understanding.

It was clear that there was also an interpretative element in the data generation part of this thesis which was supported by the outsider perspective enabling a more reflective, but not objective, stance to be adopted. I remind

myself that although my experience is similar I am not a consultant and cannot truly understand the experience of establishing and communicating an end of life prognosis nor of referral decision making. Our life-worlds are different.

Two of the oncologists, Eve and Greg, were individuals I knew and had worked with clinically and strategically over a number of years, neither felt this was an ethical or professional issue, nor a conflict of interest. For me there was the requirement of ensuring the research process was conscientious. It felt important to try and obliterate any prior knowledge and preconceptions to ensure that the interview dialogue and subsequent analysis dealt with what was actually said, that they were not mis-represented. I was also concerned as to how my past relationship would impact on the interview either enabling or hindering the encounter.

All the participants involved appeared highly articulate and 'knowing', the potential risk being that they could have produced abstract impersonal accounts missing the personal and unique qualities intrinsic to the phenomenological approach (Crotty 1998). As experienced clinicians I was aware that the achieving of rich responses was dependent on the perceived importance to them of the issue or experience being explored. All the respondents engaged supportively and the interviews provided much personal and valuable information. Establishing a relationship enabled the gleaning of some 'rich raw and powerful' data, most of the consultants appeared less protected and more open than anticipated.

There was a concurrence between the consultants' perspectives and my agenda which was facilitated by these open ended questions and a flexible personal style which appeared to encourage reflection and less guarded responses, more 'opening up'. Smith et al (2009) offer this as a strength in IPA research.

Finally, this thesis may have also been shaped by institutional and practical constraints related to institutional concerns, the role of mentors and

supervisors and my position as a doctoral student who needed to successfully complete an acceptable thesis.

## **12.6 CONCLUSION**

This chapter has attempted to consider issues of reflexivity and openness, quality and validity by applying Yardley's criteria (Yardley 2000, 2008). It is worth acknowledging that whilst demonstrating openness and awareness is important it does not necessarily add to the credibility or accuracy of the data presented in the thesis. It has also presented a reflective narrative of my research journey and in the generation of this thesis.



## **CHAPTER 13 - CONCLUSION**

**In the midst of the constant noise of our modern world, we need to create sufficient silence to hear ourselves and others. (Fletcher et al 2001:23).**

### **13.1 SUMMARISING THE STUDY**

The study described in this thesis sets out to consider the factors that may contribute to medical consultants' referral practices to Specialist Palliative Care Services (SPCS) in Wales, specifically exploring the factors acting as enablers or barriers to this.

The experience, (as described in the interview narratives) of each of the 10 consultants was presented together with descriptive, linguistic and conceptual analysis that enabled the identification of individual and shared themes. These data based chapters highlight the personal and professional and the structural and theoretical factors impacting on their referral decisions. The phenomenological and interpretative aspects of IPA informed the discussion chapters. Structural and clinical perspectives together with philosophical, phenomenological, linguistic and psychological theories were used as a framework to achieve an understanding of their clinical thinking and knowing in practice.

The previous chapter considered the issues of quality and validity, presenting personal reflections in relation to the conduct of the study and its underpinning philosophical and methodological approaches. This concluding chapter identifies the key aspects emerging from the completion of the thesis and considers their implications for policy, practice and education in relation to end of life care. It will also attempt to explicate the original contribution made by this PhD thesis and consider where next in relation to post-doctoral activity.

The following research questions were presented at the start of the thesis:

- Is there is a significant relationship between physicians perceptions and attitudes towards palliative care and their referral decisions?
- What is their view of the appropriateness of palliative care for differing populations?

- Is there a difference between consultants working with cancer and non-cancer patient populations?

These questions have been answered in part by achieving an understanding that clinical thinking and knowledge (both personal and professional) impacts on referral decision making and that the structural and theoretical contexts of health care impact on individual practice. What became more apparent was that IPA's approach supporting multi-layered exploration enabled the complexity of the consultants' stories and experiences to be heard.

### **13.2 KEY LESSONS ARISING FROM THIS STUDY**

The structural background of the macro, meso and micro levels of health care organisation and delivery locate the thesis within the complex arena of contemporary health care. Although much of the work in this thesis concentrates on the micro level of work, the direct day to day practice that shapes the experiences of the consultants. It became apparent that all the consultants' experiences were influenced by the contingencies between the macro and meso levels of the organisation and their impact on practice.

Consideration of the historical, political and evolutionary development of palliative care made it clear how the multitude of external pressures and the speed with which they emerged have directly impacted on individual practice. New strategic initiatives have led to challenges in the organisation and delivery of all services. Not always for the better. The consultants' experiences reflect uncertainty and concern particularly in relation to resource and geographical inequity. Their experiences are consistent with what is already known about the tensions of organisational and interagency working both within and across specialities.

The consultants' stories demonstrated their understanding and explicit awareness of the structural context of health care and its impact on the individual practitioner and patient (Flood 2010). Their practice, as individuals and shared across specialist groups, was influenced by the need to meet standards and targets set by the Welsh Government the implementation of which they describe as being

both constrained and enabled by local organisational and resource factors. The current strategic and organisational flux impacts on resourcing. For example the lack of availability of heart failure specialist nurses or community based therapy services for all patient groups.

The interview data clearly demonstrated that the individual consultants' practice requires them to function simultaneously at the macro, meso and micro levels of health care. This is clearly embedded in their practice and found in the descriptions of their experience. This adds dissonance and complexity to their clinical role where change at one level, for example the strategic requirement to extend palliative care to those with a non-cancer diagnosis, has the potential to be felt at the other levels.

In exploring the enabling and hindering factors to referral there was a clear difference between those internally and externally influenced. The external factors enabling and hindering access to specialist services were more likely to be related to the macro and meso levels of health care, these factors were generally externally imposed on the individual practitioner and their practice. Particular examples relate to referral guidelines and protocols produced by provider organisations such as hospices in supporting access for non-cancer patients, or the strategic direction from the Welsh Government in recommending the adoption of the Integrated Care Pathway for the Last Days of Life (2006) as being a best practice approach. Their recommendation was made for all patients at the end of life despite it being conceived to meet the particular needs of cancer patients. The cardiologists and old age psychiatrists mentioned its use as being problematic (as well as being helpful in some respects) as its use is predicated on the requirement to diagnose dying which, as reported in the literature and the participants narratives, is difficult for their patient groups.

The strategic and organisational requirement for prognostication, as a means for identifying end of life and as a requirement to potentially access services, is described as problematic at a clinical and practical level. At the micro level of care it was the factors associated with disease trajectories and difficulties in

prognostication which together with the consultants privileging of their own clinical knowing and thinking had direct impact on their perceptions of palliative care and consequent referral decisions. This tension is also apparent in the consultants' described perceptions of palliative care.

In contrast many of the barriers to referral were internal, informed by them as individuals and the micropolitics of practice. Loss and grief at a personal level, their stories of memorable patients or professional colleagues all had an impact on their clinical thinking and knowing. Examples in the oncologists' stories gave an indication of how these factors influenced their perception and engagement with their palliative care colleagues. In relation to personal experience: there was an equal split in each specialist group between those with or without personal experience of death and dying in close family members. This split was not predetermined and was only revealed at the time of the interviews.

The mixture of the structural and theoretical contexts supporting analysis enabled a deeper understanding of the consultants' experience. It specifically made more apparent the more personal aspects of their experience and its impact on their knowing and thinking as nested in their practice.

Expertise in medicine is domain specific, this is reflected in the interviews and experiences of all the consultants. For the cardiologists, oncologists and old age psychiatrists their specialist practice is legitimised by the substantive body of knowledge they possess and command together with the specific skill set and techniques they possess in applying that knowledge to the specialist area of practice. All privileged their unique body of knowledge which they perceived would be lost to their patients if a palliative care referral were made. Most recognised the value of palliative care but also acknowledged its limitations.

For the cardiologists and old age psychiatrists there appear to be more concerns in considering referral. Their specialist knowledge has a therapeutic primacy. Active management of heart failure needs the skills of a cardiologist. The management of advanced dementia relies on the specialist skills of old age

psychiatrists. Both consultant groups indicate that the disease trajectories, difficulties in prognostication and the negative connotations of palliative care would also make them hesitant to refer.

Specifically establishing and communicating an end of life prognosis is complicated by its perceived negative consequences to them as individuals, such as voodoo kills and the self fulfilling prophecy (as discussed earlier in Chapter 10) and by the practical difficulties associated with the heart failure and dementia disease trajectories. As demonstrated by previous studies prognostication is also troubling personally related to the perceived negative consequences of prediction (Christakis 1999).

Palliative care is only helpful in specific circumstances rather than being routinely offered. The cardiologists and old age psychiatrists articulated the potential benefits of a shared care approach (becoming more present in the literature) using palliative care as a resource to them rather than as a direct care provider. The only exceptions made were in relation to the accessing of in-patient hospice care or specialist out-of-hours community support.

The oncologists adopted a more inclusive approach seeing palliative care as part of the cancer patients' journey, this may relate to the historical relationship between the specialities and the trajectory of cancer which makes it easier to diagnose dying. There is evidence that referral for oncologists and thus for cancer patients is more routine and acceptable. The skill set of palliative care having been honed by familiarity in caring for cancer patients at the end of life.

The consultants described, interpreted experiences demonstrate clinical thinking and knowing that appears as the 'exercise of clinical judgement'. In relation to referral decision making, for the individual patient their clinical thinking, knowledge and the context of care acts as a guide to whether direct referral would be of benefit or whether skills of SPC could be used indirectly as a resource or consultancy service.

The virtual concept of clinical mindlines was an exemplar in all the consultants' stories of their clinical thinking and knowing in dealing with complex situations. For the cardiologists and old age psychiatrists there appeared to be an implicit and shared awareness of the requirement to make a prognosis but an understanding as part of their tacit and empirical knowing influenced their decisions to withhold or share that prognosis. This was the case specifically in relation to establishing the 'tipping point' between active and palliative care. Their experiences were a basis for consequent action or inaction in relation to referral decision making.

More uniquely some of their individual perceptions of palliative care appear negative, this was most powerfully demonstrated by their language, use of metaphor and binary opposites in the descriptive and conceptual analysis of their experience. The cardiologists' language conveyed the sense that palliative care was likely to be deleterious; the primacy of their specialist knowledge and skills enabled them to maintain an optimistic approach to care for their heart failure patients. Palliative care was a resource for them, only rarely was it appropriate for them to have direct contact with heart failure patients.

The consultants' perspectives of end of life are also characterised by implicit theoretical and philosophical concepts that appear to influence their practice. Their individual realities were influenced by the life-world, which moves their experience from the epistemological to the ontological and their habitus which for most consultants was unquestioned because it was an inherent part of their professional behaviour.

In considering whether the professionals' specific knowledge benefits the service user or the profession it represents, there appear to be links with Aristotles' notion of phronesis that their knowledge is used for the good, to benefit their patients and the wider health and social care arena.

Specific medical knowledge is of value for them working in a pluralistic multiprofessional health and social care sector. The core elements of their described experiences demonstrate that the welfare of individual patients, the

service user, is their prime concern. Their therapeutic skill set and empirical knowledge is enhanced by the human aspects of clinical practice and informed by their personal and professional experiences. Their unique body of medical knowledge and status also privileges them as being clinically responsible for patient care and having the leadership role in clinical decision making. Thus it benefits both.

### **13.3 THE ORIGINAL CONTRIBUTION MADE BY THIS THESIS AND WHERE NEXT**

The original contribution made by this study lies in a number of areas. There is originality in exploring the personal and professional experiences of medical consultants in relation to end of life care and how these impact on their referral decisions. In the consultants' stories there appears to be a complex interplay between the personal and the professional, the consultants' role demonstrates shared but also unique and personal contingencies.

Comparing cardiologists, oncologists and old age psychiatrists provided useful insight into their specialist life-world of practice. The clinical diagnoses exemplars of heart failure, cancer and dementia demonstrated the array of specialist skills and unique body of knowledge that was employed in the care of their patients. What emerged was an understanding and appreciation of their specialist skills manifest throughout their patients' journey. Interestingly, their described experiences of practice indicated that elements of palliative care were present albeit unconsciously.

Most considered palliative care as an adjunct to their practice or as a professional resource. This is not unique but the assumption that a palliative care referral would benefit their patients was challenged as part of the exploration and areas were identified where referral would not prove helpful. This is contrary to the strategic and organisational directives related to end of life care which are predicated on the value of such a referral.

Uniquely the IPA approach demonstrated its value in this thesis as a means of getting closer to the consultants' experiences and achieving an understanding

of the factors impacting on their referral practices. The deliberate division in the literature review and the subsequent discussion chapter between the structural and theoretical contexts was consistent with the phenomenological and interpretative elements of IPA.

IPA also enabled a deeper and more personal appreciation of the complexities of their life-world in practice which as a nurse I thought I appreciated but clearly did not. The consultants see their role as the decision makers in relation to transitions to end of life care. Consistent with Gott et al's study (2011) they do not acknowledge the rest of the team in informing or participating in these decisions. Their difficulties in establishing and communicating an end of life prognosis and the personal and professional responsibility involved is not made apparent to the rest of the inter-professional team. It is hoped that publications derived from this thesis may increase nurses (and perhaps other health care professionals) understanding of the complexities and responsibilities inherent in the consultants' role especially in relation to diagnosing dying.

The key findings are consistent with what is already known about difficulties in prognostication associated with trajectories of care and transitions. The disease trajectories at the end of life are liable to become increasingly complex both from disease related and organisational perspectives. The responses to these difficulties give the consultants options in clinical management.

To the best of my knowledge the IPA approach has not been applied to this particular professional group in relation to end of life referral practices. Its detailed approach to multi-layered data analysis gives further strength to this study. The purposive sample of participants suggested that the consultants who were interested were more likely to participate and thus the conclusions may be less generalisable but still of value.

An original contribution is made by increasing understanding of the external influences of the macro, meso and micro levels of health care on the



individual experiences of the participants. Specifically how the strategic and organisational requirements and demands, the lack of human and material resources, impact on their clinical practice and care of individual patients.

Although education was not explicitly discussed in the thesis, clinical knowing and thinking was an essential factor impacting on referral decision making. The Welsh Government palliative care strategy requires an interface between providers to achieve optimum end of life care primarily focussed on education. During production of the thesis I have been involved in a peer learning project which has developed a shared learning programme between heart failure and palliative care nurse specialists. The purpose was to inform the practice and upskill both professional groups by developing a shared understanding and competence. It was based on the premise that not all patients require SPC, identification of those who might benefit from direct contact or those who would benefit from the consultancy and resource elements of SPCS in enhancing their own practice. What is uniquely suggested is a recursive approach in practice between the specialist groups.

This thesis combined a social constructionist interest in epistemology and use of language together with an interest in the experiential aspects of the medical encounter from the perspective of the medical consultants. In the discussion section it offered an eclectic perspective in approaching the same research problem from different theoretical and methodological angles. Not perhaps unique but helpful and essential in supporting understanding.

In this thesis the consultants' reflections on their experiences and decision making mirrors in part the complexity of medical practice ethnographically observed by Montgomery (2006) which perhaps supports the value of their personal reflection:

It [*medical practice*] is far more than a body of scientific knowledge and a collection of well-practiced skills, although both are essential. It is the conjunction of the two: the rational, clinically experienced, and scientifically informed care of sick people. Its essential virtue is clinical judgement, the practical reasoning or phronesis that enables physicians to fit their knowledge and

experience to the circumstances of each patient. Details of human biology and countless bits of technological information are called from memory, along with their own experiences and those reported by others, and the whole is focused by (and on) the details of a particular patient's illness p.33.

This thesis explored the myriad of factors impacting on referral decision making and importantly considers the advantages and disadvantages of a palliative care referral on different patient groups and the physicians involved in their care. It has uniquely focussed on their individual experiences, as professionals and people, acting as a barrier or enabler to referral.

Personally the thesis journey has made me more curious and has made me question my understanding of palliative care, its place in contemporary health care and the clinical complexity inherent in care at the end of life. It has felt like 'Wittgenstein's ladder' providing the initial footing prior to perhaps undertaking further research. The study has highlighted important issues for future enquiry, some of which may be developed as part of post-doctoral activity. In line with UK policy directives for example, further exploring the personal and professional perspectives of each consultant group would be timely. Focussing specifically on the role of team members in helping or hindering the transitions to palliative care and considering the impact of the acute hospital setting would potentially offer rich information (Gott et al 2011). Following on from the national clinical audit of dementia (RCP 2011), identifying the need for significant improvements in the approach to care delivery and staff education, the old age psychiatrists might be the first group for further study. Also acknowledging strategic and organisation directives this information may help facilitate the development of bespoke models of education and service delivery supporting the shared care approach to end of life care supported by the participants in the thesis (WG 2009; GMC 2010; DH 2011a, 2011b; Hughes-Hallett et al 2011).

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**APPENDIX 1 –  
THE LITERATURE SEARCH STRATEGY.**

The literature was derived from systematic scoping searches of eight health and social science electronic databases, MEDLINE (Ovid), CINAHL, AMED, EMBASE, BNI, Clin Psych, EBSCO and PubMed (see Page 13 of the thesis). The initial searches were undertaken in January to March 2007 prior to the development and submission of the research proposal. They were repeated in November 2009 and May 2010. Daily Zetoc Alerts were set up from April 2007 onwards to ensure current evidence and opinion informed the thesis.

The preliminary search supported 4 themes regarding access to SPCS:

1. clinical diagnosis (cancer and non cancer) and referral practices
2. social inequalities (age, ethnicity, rurality, deprivation)
3. service inequalities (availability, recognition of need)
4. physician related issues (organisational, personal, perceptions of palliative care)

these were then expanded to provide more precise search terms for each domain:

1. cancer, terminally ill, non-cancer, palliative care, end of life, referral
2. terminally ill, palliative care, end of life, referral, age, gender, ethnicity, social factors, disability
3. terminally ill, palliative care, end of life, referral, palliative care services
4. physicians, palliative care, referral practices, decision making.

The following initial Ovid (Medline) Search Strategy search terms and limits provide an example of those used for searching the other databases in relation to physicians, palliative care, referral practices and decision making.

	<b>Search Term</b>	<b>Hits</b>
<b>1</b>	<b>palliative care/</b>	<b>14246</b>
<b>2</b>	<b>exp terminal care/</b>	<b>14371</b>
<b>3</b>	<b>terminally ill/</b>	<b>2160</b>
<b>4</b>	<b>or/1-3</b>	<b>26298</b>
<b>5</b>	<b>Prognosis/</b>	<b>109098</b>
<b>6</b>	<b>exp decision making/ or judgement/</b>	<b>42050</b>



7	5 or 6	150314
8	4 and 7	3627
9	exp “Referral and Consultation”/	19537
10	exp interprofessional relations/	16776
11	exp attitude of health personnel/	46426
12	exp physician patient relations/	19050
13	exp nurse patient relations/	9639
14	exp attitude to death/	4261
15	(intuit\$ or predict\$ or forecast\$ or prophes\$ or feel\$). tw.	302584
16	or/9-15	398717
17	8 and 16	1265
18	Limit 17 to (English language and “all adult(19 plus years)”) )	556
19	From 18 keep 1-556	556

Database searches during February to May 2010 yielded the following number of references; further exclusions were added at this time: advance directive discussions, euthanasia, physician assisted suicide, intensive care and brain death.

Database	Number of References before the further exclusions
Medline	2488
AMED	980
CINAHL	3149
EMBASE	921
BNI	390
Total	7928
Total post exclusions	5068
Duplicates identified by ‘end-note’	1179
Total	3889

The abstracts for these articles were read and categorised as:

A = very relevant

B = possibly relevant

C = uncertain

D = not useful.

My categorisation was randomly checked by a specialist librarian colleague. A considerable amount of literature was read which either directly informed the thesis or provided an eclectic and comprehensive background. Almost 500 references are cited in the compilation reference list.

Additional searches were made of global and national organisation and governmental websites, together with those of voluntary organisations, lobbying and patient groups.

Backward chaining was employed to identify seminal works which informed the structural and theoretical contexts in which the thesis was located. Attendance at an IPA Masterclass in April 2011 and advice from my supervisors and colleagues signposted me to various texts that might inform the thesis and in many cases this was helpful. Examples derived from this process include the concepts of habitus and clinical mindlines.

## **APPENDIX 2 – THE ETHICAL REVIEW PROCESS.**

- Submission of my research proposal to the internal school [Research Review and Ethics Screening Committee](#) (RRESC) for scientific review and ethics screening *before* they are sent for review to any external body NHS research ethics committees. Its' purpose being to ensure internal quality and act as a resource signposting and guiding me towards an NHS route for final ethics approval as my participants are NHS staff.
- Cardiff University agreed to act as the sponsor, required under the Research Governance Framework for Health and Social Care and/or the Medicines for Human Use (Clinical Trials) Regulations 2004.
- The Research Governance Process was ensured by the gaining of external ethical approval, completion of the online Integrated Research Application System (IRAS) documentation which supported the completion of multiple application forms for both the Wales NHS Research Ethics Committee (WREC) and the host organisation, the University Local Health Board (ULHB), Research and Development Committee [www.myresearchproject.org.uk](http://www.myresearchproject.org.uk).
- WREC was chosen as it supported all Wales approval for the thesis, if recruitment was not successful in one LHB it would be an easier process to approach another site with All-Wales approval being already granted.
- These forms were submitted together with the study protocol (which included interview questions) and documentation (consent forms, invitation letter and participant information sheets).
- Attendance at WREC was both a supportive and challenging experience, the committee expressed no concerns as to the ethical probity of the study and approved it unconditionally in September 2009.
- Members of the committee raised concerns as to its "doability" and feasibility. Two members both medical consultants, were uncertain as to whether busy physicians would be willing to give up their time to participate especially as the study did not directly appear to benefit them or their patients. They also questioned how comfortable and responsive would participants be with the proposed open-ended interview structure and the personal nature of some of the questions.
- These concerns took the edge off receiving unconditional approval and resulted in much discussion with my supervisor and the WREC co-ordinator. A reserve position was discussed if needed, this would replace the proposed participant group of physicians by Clinical Nurse Specialists. This would necessitate substantial amendments ethical approval through WREC. Fortunately this was not required.
- The LHB R&D and Site Specific approval process was initiated in parallel with WREC. As a professional courtesy and to support

approval and access the clinical directors from each speciality were approached via email explaining the study and requesting their approval to establish contacts with the medical consultants working in their directorate. All responded and supported access although one was concerned that the physicians' participation should take place as part of the working day and not intrude on their private time.

- This email correspondence was consistently copied to the LHB R&D team. Subsequent approval was received and accessing of participants and data collection commenced in April 2010.
- The delay between obtaining ethical approval and data collection was related to personal events necessitating a break in research activity.
- Regular annual contact has been maintained with WREC through the annual report process and the substantial amendments approval required in order to use Old Age Psychiatrists as a further participant group and informing them of a change in academic supervisor.
- Annual contact has been maintained with the LHB with completion of the annual review proforma and providing notification to them of the WREC substantial amendments proposal.
- Substantial amendments approval from WREC and R&D was obtained and the second stage of data collection commenced at the end of October 2010.

**APPENDIX 3 –  
PARTICIPANT INVITATION LETTER.**



Cardiff School of Nursing and Midwifery Studies,  
Cardiff University, 5<sup>th</sup> Floor Room 12, Eastgate House,  
35-43, Newport Road, Cardiff CF24 0AB

Date: 25<sup>th</sup> March 2010

**Study Title: Practitioners and referral decision-making in end of life care.**

Dear

My name is Sally Anstey and I am a lecturer and doctoral student in the School of Nursing and Midwifery Studies at Cardiff University. We had email contact a few months ago regarding my research study to fulfil the requirements of my doctorate, and I would now like to invite you to participate in a single interview.

I am exploring the factors which contribute to clinical decision making and influence medical consultants to refer, or not refer, their patients to specialist palliative care services.

I am asking consultants working in the clinical specialities of ... working within ...to participate. The interview would take place within working hours and experience suggests that it will take no longer than an hour. The Trust have given R&D approval for the study.

I have recently been working with ...

Who suggested you would be an important person to recruit to the study.

Further and more detailed information is contained in the participant information sheet accompanying this letter and I will be happy to answer any questions you have about the study.

Thank you for considering participating in this study. If you are willing to participate please complete the details below and return them to me in the enclosed SAE.

With kind regards,

Sally Anstey RGN, DipN (Wales), PGCE, MSc (London).Lecturer: Adult Nursing/End of Life Care.

Telephone: 07855394379. Email: [anstey1@cardiff.ac.uk](mailto:anstey1@cardiff.ac.uk)

Reply Slip.

**Agreement to contact and participation in the research study  
Practitioners and referral decision-making in end of life care**

I agree to being contacted in relation to the above study.

Name

Signature

Date

Please indicate your preferred method of contact and provide details:

Email

Telephone

Personal letter

Other

Thank you  
Sally Anstey.



## **APPENDIX 4 - PARTICIPANT INFORMATION SHEET**

Participant Information Sheet  
Medical Consultants.

Study title: Practitioners and referral decision making in end of life care.

1. An invitation to take part in a research study

I would like to invite you to take part in a research study. Before you decide, it is important to understand why the research is being done and what it would involve for you. Please take time to read the following information and ask me if there is anything that is not clear or if you would like more information.

2. What is the purpose of the study?

The intention of this study is to explore what factors contribute to clinical decision making and influence medical consultants to refer, or not refer, their patients to specialist palliative care services

3. Why have I been invited?

I am asking medical consultants working in a variety of clinical specialities in different geographical areas across Wales, providing care to NHS patients, to participate in an interview. The interview would take place within working hours.

4. Do I have to take part?

Participation in this study is completely voluntary. It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form and given a copy of both the signed form and this information sheet to keep. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, would not affect you in any way.

5. What will happen to me if I take part?

Participation in the study involves you in a single semi-structured interview. The interview will be of approximately 30-60 minutes duration. I will ask you about your experience of referring (or not) your patients to specialist palliative care services and to reflect on what factors may have influenced your decision. With your permission the interview will be digitally recorded. You will be given the opportunity to review the transcript of your interview should you wish to do so.

6. Will my taking part in this study be kept confidential?

The procedures I will use to handle, process, store and destroy all of the information I obtain about you will follow Cardiff University policies, and fulfil the requirements of the Data Protection Act 1998.

I will use a digital recorder to audio-record the interview I conduct with you. I will listen to the tapes and transcribe them word for word into a typed document. The main issues you raised in your interview and those that come from any notes taken would be drawn out. All data will be anonymised. This process would be carried out by myself and discussed with my educational supervisors. The tape recording will be destroyed after transcription has taken place.

I will store all of the electronic documents containing coded information about, and provided by, the people taking part in this study in a password-controlled computer. Only I will know this password. I will keep back-up copies of all my coded data on a second password-controlled computer.

I will use a computer software program to help me to organise and analyse all of the information I gather during this study. I will analyse your responses to draw out the key themes which I will then group and cluster with those of your colleagues working in the same speciality. I will then compare the responses of your group with those of the other specialist groups seeking to understand the similarities and differences. I will set my findings in the wider context of referral decision-making in specialist palliative care.

I will store a single copy of each original digital audio-recording file, saved on a portable digital media device, in a locked cabinet in my workplace. In this cabinet I will also store my copy of your signed consent form, and a document, which links you to the coded information given by you on the two password-controlled computers. The only individuals to have access to these files and documents will be myself and Research Governance staff working at Cardiff University. These staff may request to see my copy of your signed consent form and the data I have gathered as part of their routine audit of studies. These members of staff will have a duty of confidentiality to you as a research participant, and nothing that could reveal your identity will be disclosed outside the research site.

Following Cardiff University guidelines, all paper and electronic records associated with this study will be securely stored for a period of 15 years from the date of the last publication which uses data obtained during this investigation. After this time all records will be permanently destroyed. If I leave my post before this period of time elapses, all information gathered in this study will be passed to the care of a designated custodian. This person will have the responsibility to oversee the continued secure storage of all records, to maintain confidentiality, and to permanently destroy all paper and electronic files at the designated time.

#### 7. What will happen if I don't want to carry on with the study?

If you withdraw before I have produced my findings from the study I will not use any information you have given me in producing my thesis and I will destroy all the information you have given me.

If you withdraw after I have produced my thesis, or after I have used the information I have gathered from you to produce journal articles or conference

presentations, then I will make sure that I do not use information given by you in any further articles or presentations.

7. Expenses and payments

I am not able to pay research participants for their time. Interviews will take place at your place of work at a time convenient to you.

8. What are the possible disadvantages and risks of taking part?

I do not foresee any disadvantages or risks to you in taking part in the study.

9. What are the possible benefits of taking part?

I cannot promise the study will help you personally but the information that you provide may be used to shape policy with regards to the future development of specialist palliative care services

10. What if there is a problem?

Any complaint about the way you have been treated during the study or any possible harm you might suffer will be addressed. If you have a concern about any aspect of this study, you should ask to speak to me. I will do my best to answer your questions, and my contact details are given at the end of this document.

If you remain unhappy and wish to complain formally, you can do this by contacting Dr Kathryn Pittard Davies, Head of Research Policy and Management Cardiff University. You can write to Dr Pittard Davies at the Research and Commercial Division, Cardiff University, McKenzie House, 30-36 Newport Road, Cardiff CF24 0DE, or contact her by either telephone on 029 20879274 or via email at [davieskp2@cardiff.ac.uk](mailto:davieskp2@cardiff.ac.uk).

10. What will happen to the results of the research study?

At the study's end I will be producing a PhD thesis, based on what I have found and intend to present my findings at conferences. I will also write articles for publication in journals in order that other people can learn from this study. In my thesis, and in all of my other presentations and publications, I will use verbatim quotes as illustration of the themes identified from the interviews. Names of participants taking part in this study and the geographical areas where they work will not be given in any of the publications and presentations produced.

11. Who is organising and funding the research?

This study is being undertaken in part fulfilment of a PhD and as such is sponsored by Cardiff University with whom I am registered as a student. The study fits into the Research Strategy developed in the Cardiff School of Nursing and Midwifery Studies.

12. Who has reviewed the study?

This study has been reviewed by the All Wales Research Ethics Committee as part of the Integrated Research Application System (IRAS) which involves research and development and site specific approval.

Further information and contact details:

For further information on this study you are invited to contact either my academic supervisor or myself using the following details:

Sally Anstey  
Cardiff School of Nursing and Midwifery Studies  
Cardiff University  
5<sup>th</sup> Floor Eastgate House  
35-43, Newport Road  
Cardiff CF24 0AB  
Telephone: 02920 917788  
Mobile 07855394379  
Email: [anstey1@cardiff.ac.uk](mailto:anstey1@cardiff.ac.uk)

Academic supervisor  
Dr Jane Harden  
Director of Postgraduate Studies (Taught)  
Cardiff School of Nursing & Midwifery Studies  
Cardiff University Room 709  
Eastgate House  
35-43 Newport Road  
Cardiff CF24 0AB  
Tel: 029 2091 7725  
Mobile: 07736 933547  
[hardenj@cardiff.ac.uk](mailto:hardenj@cardiff.ac.uk)

## **APPENDIX 5 – CONSENT FORM**

**Consent form**

Title of Study: "Practitioners and referral decision-making in end of life care"

Name of Researcher: Sally Anstey.

	Please initial box
I confirm that I have read and understand the Participant Information Sheet, for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	<input type="checkbox"/>
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.	<input type="checkbox"/>
I understand that data collected during the study may be looked at by Research Governance staff working in Cardiff University, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	<input type="checkbox"/>
I agree to the use of audio-recording, and understand that verbatim quotations from my interview may be used anonymously in the report produced from this study and in papers produced for publication and for conference presentation, but I can withdraw the use of any part of the material at any time before the report is published.	<input type="checkbox"/>
I agree to take part in the above study.	<input type="checkbox"/>

\_\_\_\_\_  
Name of participant

\_\_\_\_\_  
Date

Signature

\_\_\_\_\_  
Name of person taking consent

\_\_\_\_\_  
Date

Signature

When completed, 1 for participant; 1 for researcher site file.

**APPENDIX 6 –  
ETHICAL APPROVAL LETTER.**



Research Ethics  
Committee for Wales

Chairman/Cardeirydd :  
Dr Gordon Taylor



Ymchwil Ethegau  
Aml-Ganolfan  
yng Nghymru

Administrator/Gweinyddes:  
Dr. Corinne Scott

Churchill House, Fourth Floor, 17 Churchill Way, Cardiff, CF10 2TW  
Ty Churchill, 17 Ffordd Churchill, Caerdydd, CF10 2TW

Website: <http://www.nres.npsa.nhs.uk>  
e-mail: [corinne.scott@bsc.wales.nhs.uk](mailto:corinne.scott@bsc.wales.nhs.uk)

Fax No. 029 2037 6824

Telephone enquiries to: 029 2037 6829

15 September 2009

Ms Sally Anstey  
Lecturer and PhD Student  
Cardiff University  
School of Nursing and Midwifery

Dear Ms Anstey

<b>Study Title:</b>	<b>An exploration of factors influencing referral to specialist palliative care services for patients with cancer and non-cancer conditions.</b>
<b>REC reference number:</b>	<b>09/MRE09/43</b>
<b>Protocol number:</b>	<b>Final draft</b>

The Research Ethics Committee reviewed the above application at the meeting held on 10 September 2009. Thank you for attending to discuss the study.

#### **Ethical opinion**

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

#### **Ethical review of research sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

### **Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>. Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

**It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

### **Approved documents**

The documents reviewed and approved at the meeting were:

Document	Version	Date
Covering Letter	signed Ms. Anstey	24 August 2009
REC application	signed Ms. Anstey, Mr. Matthew Harris (sponsor), and Professor Paul Bennett (supervisor)	27 August 2009
Protocol	Final draft	31 July 2009
Investigator CV	Ms. Anstey	31 July 2009
Participant Information Sheet: Medical consultants	Final draft	29 July 2009
Participant Consent Form		31 July 2009
Letter of invitation to participant	and reply slip, final version	31 July 2009
Evidence of insurance or indemnity	Zurich Minicupal certificate of insurance - Cardiff University - expires 31 July 2010.	
Investigator CV	Professor Bennett	31 July 2009

### **Membership of the Committee**

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### **After ethical review**

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- ☐ Notifying substantial amendments
- ☐ Adding new sites and investigators
- ☐ Progress and safety reports
- ☐ Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If

you would like to join our Reference Group please email [referencegroup@nres.npsa.nhs.uk](mailto:referencegroup@nres.npsa.nhs.uk).

<b>09/MRE09/43</b>	<b>Please quote this number on all correspondence</b>
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With the Committee’s best wishes for the success of this project

Yours sincerely

**Dr Gordon Taylor**  
**Chairman**

Email: [corinne.scott@bsc.wales.nhs.uk](mailto:corinne.scott@bsc.wales.nhs.uk)

Enclosures : List of names and professions of members who were present at the meeting and those who submitted written comments  
“After ethical review – guidance for researchers”

**APPENDIX 7 –  
SCANNED PICTURE OF POST-IT NOTES  
SUPPORTING DATA ANALYSIS.**

