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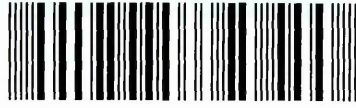
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Older People's Experience of Cancer Pain

A qualitative enquiry

Margaret Mary Dunham

A thesis submitted in partial fulfilment of the requirements of
Sheffield Hallam University
for the degree of Doctor of Philosophy

July 2015

Declaration

I declare that this is all my own original work and has not been submitted for any other academic awards at any other Higher Education Institution.

M.M. Dunham

M. M. Dunham

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Abstract

Cancer is mainly a disease of older people; older people with cancer experience complex symptoms, which may include pain. Pain is also a significant concern for many people living and dying with cancer, and may be particularly difficult for people with co-morbidities of ageing. Pain which is unrecognised and untreated may significantly affect quality of life and function. In particular, there is limited knowledge of how older people experience cancer pain and how this affects their daily lives.

This study aimed to capture the experiences of pain of older people with cancer, consider how older people construct the experience of cancer pain and how this is informed by their expectations and experiences. The methodological approach of Interpretative Phenomenological Analysis informed a qualitative diary-interview study which was conducted with purposively selected older people, diagnosed with cancer and in receipt of specialist palliative care.

Nine older people with cancer (aged 67-88) living independently were interviewed either in the hospice day centre or their domestic home. Major themes identified were: 'Better to be old than to be dying with cancer', 'Maintaining control and independence', 'Loss of identity - grieving for a former self', 'Dislike of analgesia' and 'Dismissal or denial of pain'.

Collecting data about cancer pain, from older people who may be vulnerable and in receipt of specialist palliative care, proved ethically and practically challenging. Clinical pain assessment alone, without listening to people's pain stories, does not always identify pain or problems with daily living. Understanding the communication needs of older people is an important precursor to understanding their health care needs. Appreciation of the individuality of the lived experience of cancer may advance our understanding of pain and end of life care.

This study adds to the existing body of knowledge about the needs of older people with cancer pain and offers unique theoretical, methodological and practical contributions to support the body of evidence about older people's needs.

Glossary of Terms

Hospice Care

The modern hospice movement has developed in response to the complexities of living and dying with cancer or other terminal disease, as a professional discipline with expertise in symptom management, psychosocial and spiritual care. They provide a range of services for conditions where curative treatment is no longer an option, and people are approaching the end of their life (National Council for Palliative Care 2006, Macmillan Cancer Support 2012).

Older People

The UK National Service Framework for Older People describes classifications of 'older age' in 3 ways (DH 2001). *Entering old age* is described as when someone has completed their paid employment and aged 50. A *transitional phase* is described where the older person remains relatively active but is becoming more frail and this is in the seventh or eighth decade. *Frail older people* are more likely to have a severe debilitating illness. Today one fifth of the UK population is aged 60 or older and the UK Office for National Statistics defines older people as those aged 50 and over (Office for National Statistics 2009). Thus there is no UK consensus and definition for older people and many studies and clinical trials deliberately exclude people aged 60 and over from participation (Bartlett *et al* 2005, Bugeja *et al* 2007). For the purpose of this study older people are defined as those aged 60 years or over.

Experience

The term 'experience' is used in the literature variously to describe either the narrative account of open questioning and interview presented in a qualitative format or is measured with quality of life tools in quantitative research (Dawson *et al* 2010, Barry & Edgman-Levitan 2012). In describing pain experience the quantitative and qualitative provide perspectives on pain experience that are not totally exclusive and may occasionally be contradictory, if for example pain numerical scores are low but interview data suggests that people underreport their pain (Turk & Flor 1987, Lawlor 2003). The term 'lived experience' may be defined as 'experiences that are lived' or the

first hand, personal experience of the individual (Burns & Grove 2005: 133). For practical purposes and because the proposed study is qualitative in nature, experience will be considered as the report or voice of the patient about their care which may encompass the physical and emotional experience of that care. The voice will be the care experience which the patient is willing and able to share (DH 2003).

Suffering

The term suffering is used as an adjective to describe a central element of a disease process. It is often used in the title or abstract of a study. Suffering, like pain is a subjective term and may not be the word used by people experiencing the disease. In cancer studies people are sometimes described as 'suffering from' cancer. Arguably in the context of describing a study the term 'suffering from' is merely used as a substitute for 'the experience of'. However, 'to suffer' has a much more broad and pejorative application which encompasses pain and other adverse aspects of having and living with cancer. There are also professional and lay perspectives; professionals who describe suffering may be talking about suffering from the disease where, in contrast, the experiencing person would talk of suffering from the symptoms of the disease. It is this latter definition which is probably closest to the assumptions about older people with cancer for the purpose of this study.

Palliative Care

The point at which necessary curative treatment becomes palliative, in which the primary purpose is to maintain quality of life and to relieve symptoms, may be a transitional period rather than one discreet point in time (Addington-Hall 2007:3). Furthermore the timing of when care becomes 'palliative' is disputed. The World Health Organisation (2002) has defined palliative care as:

'...an approach that improves the quality-of-life of patients and their families facing the problems associated with life-threatening illness, or 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.'

This definition may lead to problems for the practical implementation of palliative care. 'Impeccable assessment' may be problematic for a variety of reasons related to, for example, ethnicity, language and/or communication barriers. However the UK Department of Health defines palliative care within its National Service Framework for Long Term Conditions as:

'... providing active, holistic, day-to-day care to patients in the advanced stages of progressive conditions and support to their carers... but is not expected to cure the condition.'

Addington-Hall (2007:3) considered that palliative care research is about 'sick patients who are going to get sicker'. In a recent UK study of patients' perspectives on palliative care the study population were invited to participate if they defined themselves as 'living with a terminal illness' but the subjects clearly did not consider they were dying or near death (Chapple *et al* 2006). This highlights the difficulty of categorising patients for study by prognosis.

Specialist Palliative Care

Specialist palliative care (SPC) is the phrase used within UK health care to describe the recommended principles for cancer services in the UK as described in the Calman-Hine Report (DH 1995). Specialist palliative care is the active, total care of patients with progressive, advanced disease and their families. Care is provided by a multi-professional team who have undergone recognised specialist palliative care training. The aim of the care is to provide physical, psychological, social and spiritual support (National Council for Palliative Care 2006¹).

Phenomenology and IPA

Phenomenology is a philosophical stance taken by some researchers which acknowledges the importance of the individual's lived experience of particular phenomena. Phenomenology is also a qualitative approach to research and in practice has several forms. Indeed, phenomenology can be both a philosophical approach to

¹ National Council for Palliative Care (2006) Palliative Care Explained available at <http://www.ncpc.org.uk/palliative-care-explained>

qualitative research and has its own approaches regarding how data is obtained and analysed. Any data which represents the participants' lived experience of phenomena and describes their lived phenomenal experience may be used in a phenomenological study. The phenomenon, in this study, is older people's cancer pain and the type of phenomenological approach to this is used is Interpretive Phenomenological Analysis (IPA) (Smith *et al* 1999). This IPA approach to studying the experiences of people is focused on understanding the participant's perspective on an experience and is particularly suited to establishing participant's health care needs as part of an individualised and holistic approach to health. The term 'interpretative' is used to emphasise that the report of the lived experience is not direct, it is interpreted first by the participant through memory and second by the researcher through analysis of the data. This is unlike the original research undertaken by Husserl which sought a virtually un-interpreted report of phenomena, as shown by the expression 'to the things themselves' (Smith 2004).

Husserl proposed:

'... to abandon old ways of doing philosophy in favour of a return to the careful description of the 'things themselves', that is the ideal objectivities which constitute meanings. Thus, originally, phenomenology was a kind of conceptual analysis'

(Moran 2000: 74)

Construct

The research question asks 'how do older people *construct* their experiences. Construct in this context and for the purpose of this study refers to a biopsychosocial model of health care whereby people draw upon expectations, experiences and knowledge to live with and express their experiences. Living with a particular illness or associated problem may be described in terms which relate to coping or possibly catastrophising that experience.

Publications and Conference Presentations

Dunham M. Collins K. Allmark P. (2015) *The Experience of Living with Pain in Older People with Cancer: Findings from a Qualitative Study*. *British Journal of Pain* 9 (2, S1):14

Dunham M. Collins K. Allmark P. (2014) *Pain in Older People with Cancer, Findings from a qualitative study*. RDASH Grounded Research Conference. Invited Speaker

Dunham M. Collins K. Allmark P. (2014) *Older People's Cancer Pain Experience, Preliminary findings from a qualitative study*. *BMJ Supportive & Palliative Care* 4(1): A41

Dunham M. Collins K. Allmark P. (2013) *Older People with Cancer: Reflections on the Ethical and Methodological Issues of Accessing Older People in Receipt of Palliative Care*. British Society for Gerontology ERA, Oxford

Dunham M. Ingleton C. Ryan T. Gott M. (2013) *A narrative literature review of older people's cancer pain experience*. *Journal of Clinical Nursing* 22: 2100–2113

Preface

My interest in older people's cancer pain was inspired by my professional experiences as a Pain Nurse. The pain services in both hospital and community were established to support people with diagnoses of acute or chronic pain not those with complex pain problems such as older people with cancer pain. My desire to explore this through a PhD was piqued by my experience with older family members and their encounters with health care services. In reflecting on the care that my older relatives and latterly my own mother received, I resolved to give voice to their concerns.

Mum was an exceptionally bright and independent lady of 70 years who had never been admitted to hospital when she collapsed with a bowel obstruction due to ovarian cancer. She became an old lady within days and was subject to the impersonal and paternalistic model of health care which I had so frequently witnessed applied in my professional role. The person beyond the diagnosis was not visible to many and chronological age prefixed every assessment or intervention.

Pain relief was administered when the nurse or doctor thought it was needed and restricted to the local policy of an upper limit of dosage regardless of the pain she was actually experiencing. This was distressing for her and for us, her family.

Having care which centres on the person rather than the disease should be a core principle of health care delivery. Crucially, health care professionals have a duty to see the individual the person who needs care. Personhood and identity are compromised in illness (Kitwood 1997). However, adopting a person centred approach can support the care needs of the individual to enable them to maintain dignity and retain some independence (Ford & McCormack 2000, Clarke *et al* 2003).

As a daughter, observing the care my mum received made me resolve to try to improve the experience of other older people by researching to give them a voice so as to better understand their experiences.

Chapter 1

Introduction

1.1. Introduction

This thesis outlines the methods and findings of a research enquiry which considers older people's experiences of living with cancer and pain whilst accessing specialist palliative care services. This introductory chapter will provide some of the background and context to the study about older people with cancer pain. The research problem will be elaborated followed by an outline summary of the chapters and contents of the thesis, thus providing an overview of the research process and findings.

1.2 Introduction to the Research Problem

People in the UK are living much longer than previous generations yet older people's needs have been largely neglected. In particular, older people's health and social care needs in hospital and community are the current focus of much concern in the wake of recent health and social care scandals (Parliamentary and Health Service Ombudsman 2011, Best 2011, Cornwell 2012, Francis 2013). Various factors have been considered as contributing to the failings in care including a lack of leadership, inadequate training, poor staffing numbers and neglect or oversight in the planning of services for older people. However, older people have largely been excluded from health care research which establishes their needs and have been subject to marginalisation and discrimination (Equality and Human Rights Commission 2010).

Given the increasingly ageing UK and world populations it is vital to understand the health care needs of older people. Notably, within this ageing population the prevalence of disease and illness is expected to increase; in particular cancers are more prevalent with age (ONS 2012). The mortality and morbidity rates associated with cancer are known to be improving in adult populations because of earlier diagnosis. However, early diagnosis is not consistent across all age groups with many older

people diagnosed later. In practice, current guidance for routine cancer screening in the UK sets upper age limits because of presumed lower life expectancy (British Geriatrics Society 2011). Thus, it is possible that the prevalence of symptom experience may be greater in this population and compounded with the co-morbidities of ageing.

Older people have been under represented in clinical trials leaving a gap in the knowledge and benefits of treating cancers in this age group. Indeed, the recent UK Department of Health's National Awareness and Early Diagnosis Initiative specifically excluded the over 75 population from routine screening for common cancers (DH 2011). The consequent under treatment of cancers in this age group has been estimated to contribute to some 14,000 annual cancer deaths in the UK (Moller *et al* 2011, Macmillan Cancer Support 2012). In those aged under 75 years mortality rates are notably better than for those aged over 75 (National Cancer Intelligence Network 2010, 2014). This may be partially due to increased prevalence of cancers, under treatment and delayed diagnosis in the old.

Cancer is strongly associated with pain. On average 30% of patients receiving treatment for cancer experience pain, increasing to 90% in those with advanced cancer (Grossman & Staats 1994, Deandrea *et al* 2014). Cancer pain can be caused and influenced by many different physical and psychological experiences (Mantyh *et al* 2002). Pain can be experienced when a tumour presses on nerves or expands inside a hollow organ (Regan & Peng 2000). Tumours may obstruct the lymphatic system causing lymphoedema and nerve pain. Moreover severe pain may originate from bone and bone marrow infiltration (Mundy 2002). Unfortunately, radiotherapy and chemotherapy which are frequently used to treat cancer can also cause pain and lead to recurrent pain after many years (Caraceni & Portenoy 1999, DeSantis *et al* 2014).

The reality for those with cancer is that physical causes of cancer pain are varied because of the many different cancer types, sites of tumour, surgical procedures, chemotherapy and radiotherapy (Banning *et al* 1991, Twycross *et al* 1996, DeSantis *et al* 2014). Caraceni and Portenoy, in a commissioned survey for the International

Association for the Study of Pain (IASP) 1999 survey of cancer professionals, acknowledged the heterogeneous nature of the cancer pain experience. More recent survey of expert opinion has yet to agree common terms and standards for cancer pain (Kaasa *et al* 2011). Cancer pain has also been described as nociceptive (acute), neuropathic (chronic) or 'breakthrough' because of the mixture of physical events leading to the pain experience (Caraceni & Portenoy 1999, Mulvey *et al* 2014).

The problem with cancer pain is that it does not exist in isolation from other distressing symptoms (National Council for Hospice and Specialist Palliative Care Services 2003). The experience of cancer has been variously described as pain, suffering and distress with physiological, affective, sensory and sociocultural elements (Cherny *et al* 1994, Higginson *et al* 1995, Mori *et al* 2012). Frequently, pain is accompanied by fatigue, nausea and restricted mobility (Johnson *et al* 2005, Barbera *et al* 2010). There is also abundant evidence that pain management in cancer care can affect quality of life and quality of dying (Heidrich & Ward 1991, Aziz & Rowland 2003, Hewitt *et al* 2003, Luszczynska *et al* 2005, van den Beuken-van Everingen 2007). Furthermore, spiritual and existential crises are also associated with cancer pain (Halldórsdóttir & Hamrin 1996).

Given the predicted demographic changes and their anticipated effects on health care provision, the needs of older people with cancer pain are worthy of consideration. Older people with cancer are likely to have more complex health care needs requiring the combined input of geriatric and palliative care services. In the absence of understanding the nature and extent of the problem, management of pain may present a major issue for older people with cancer and their healthcare providers.

Barriers to cancer pain management, for all age groups, have been identified by the American Cancer Society's advisory group on cancer pain (American Cancer Society 2014)². These barriers include the broad areas of patient barriers, physician (health care professional) barriers and regulatory barriers or problems related to the 'system'.

² <http://www.cancer.org/aboutus/globalhealth/paincontrol>

Patient barriers include:

- Misunderstanding about treatment effects and analgesic side effects (Yates *et al* 2002, Bostrom *et al* 2004, Vallerand *et al* 2007).
- Thinking pain cannot be controlled or simply is inevitable (Pargson & Hailey 1999, Borneman *et al* 2010).
- Stoicism and reluctance to acknowledge pain and to take prescribed medication for pain (Yong *et al* 2001, Schofield *et al* 2011).
- Fears of addiction and tolerance (Delgado-Guay *et al* 2008).

Similarly carers and health professionals have fears, concerns and misunderstanding of the pain experience. Professional or carer barriers to effective cancer pain management include:

- The poor attitudes and lack of empathy of health professionals towards cancer pain and suspicions of secondary gain or malingering (Harkins *et al* 1994, Clarke *et al* 1996, McCaffery & Ferrell 1997, Weiner *et al* 1999, Lin *et al* 2000, Weiss *et al* 2001, Brown & Richardson 2005, Kappesser *et al* 2006, Lelorain *et al* 2012).
- Poor skills in pain assessment and concerns about tolerance and addiction (Bruera *et al* 2005, Jacobsen *et al* 2009).
- Gaps in knowledge and understanding of cancer pain or fear of litigation (Grossman *et al* 1991, Twycross & Fairfield 1993, Allard *et al* 2001, O'Brien & Jack 2010).
- Underestimating the older patient's pain (Closs 1994, Blomqvist & Hallberg 1999, Allcock *et al* 2002, Jakobsson *et al* 2003, Steindall *et al* 2011).

However, there is no strong evidence that directed education, which focuses on improving health care professionals' knowledge, improves the patients' pain experience (Weiss *et al* 2001, Bostrom *et al* 2004). Knowledge and skills are important but positive attitudes towards, or empathy with, another's pain experience are also important components of the caring role (Goubert *et al* 2005). For both older patients

and health care professionals the common barriers to cancer pain management are related to knowledge and level of empathy.

Organisational barriers to cancer pain management may include:

- Regulatory restrictions and inhibitory protocols for the administration of opioids at local and national levels (Dahl 2003, Cherny *et al* 2010).
- Reluctance to prescribe opioids for cancer pain on the recommendation of professional organisations (WHO 2002, Schumacher *et al* 2002, Broekmans *et al* 2004, Cherny *et al* 2006).

Without supportive policy, guidance and regulatory frameworks, knowledgeable and empathetic health care professionals will be restricted in offering the most effective care.

Unfortunately, within the UK there is minimal guidance related to pain management for older adults with cancer. The unacceptability of ageism related to older people's cancer services has been acknowledged in the UK National Health Service's Cancer Plan; however, little mention was made of pain relief only of more general symptom management (DH 2000). The National Service Framework for Older People (DH 2001) suggested that older people deserved being treated with dignity and respect and endorsed 'person-centred care'; however this document did not mention the term 'pain' once. This concept of patient centred care is underpinned by the assumption that patients' experiences matter. If patient experience is important then study of this could be used to inform effective pain assessment and management (Vanderford *et al* 1997, Rycroft-Malone *et al* 2004).

1.2.1 Defining Ageing

Definitions of ageing and old age are varied between cultural groups and populations. In practice, there is no consensus about when someone becomes old. Older people may be defined by health status, chronological age, cultural seniority or employment status (Walker 2004, Walker & Naegele 2009) and popular myths and stereotypes of

ageing are widespread in the public presentation of old age. Indeed, the terms for age and ageing vary across continents and research groups to include terms such as 'senior', 'elderly', 'geriatric' or simply 'aged' (Extermann *et al* 2005, Extermann 2010). Each term is suited to one context and may be considered pejorative in another.

The norms of ageing may also be contextual to temporal, cultural and geographical locations (Neugarten 1996). Ageing is further socially and culturally defined through the context of socioeconomic status. In the industrialised world economic affluence and greater life expectancy has led to a period of older age called retirement. The age for retirement varies between industrialised nations, for example, until recently, Iceland had a retirement age of 67 for men and women contrasted with the UK retirement age of 65 (now 67 for many) (OECD 2013). Within the UK, the current age of retirement is usually the basis of determining old age. This would suggest that as the retirement age rises that the start of old age rises correspondingly (Coe & Zamorro 2011). Indeed, this point in the chronological life span may herald years of healthy participation in fulfilling hobbies and activities.

Ageing may also indicate a decline in health status associated with deteriorating physical and mental functioning. Indeed, old age has been equated with increasing frailty (Biggs & Powell 2001). The central tenet of this construction is that ageing is a pathological process which leads to the inevitable breakdown of the body's biological processes. Therefore, for those experiencing chronological old age, there may be an acceptance of increasing health care problems and a corresponding decline in function which is considered normal.

It is acknowledged that older people may use a greater proportion of health care services because of their increasing morbidity, which is not reflected in available service provision (Burholt & Windle 2006, National Audit Office 2012). Therefore, functional decline and increasing frailty may define the professional and the individual's construction of old age, whether as observed or experienced, but there is no clear consensus on a definition of old age. Consequently, the UK Government and The UK Department of Health have defended the right of access to healthcare services

based on individual assessment of potential health benefit rather than chronological age and condemn age discrimination in health care provision (Centre for Policy on Ageing 2009, Government Equalities Office 2010).

UK life expectancy has increased significantly in the second half of the 20th century (ONS 2012). Thus, health care services which once targeted an 'old' population have had to redefine terms and what it means to be 'old' in the 21st century. In stark contrast, parts of the developing world, still experience high infant mortality and early death due to poor health care provision and socioeconomic deprivation leading to lower locally agreed definitions of ageing. Even, within the socially and culturally stratified UK populations, there may be further age definitions and social identities to be considered such as the individuals' definitions, effects of socioeconomic deprivation and the contrasting media representations of ageing (Gilleard & Higgs 2011). Thus, chronological age is not the sole determinant of old age. Also, it is important to note that not all older people should be considered as vulnerable (Lievesley 2009). In the UK, vulnerable groups are defined by statute in terms of their health or social care needs, but not their chronological age; as such all older people are not considered vulnerable (DH 2006, 2012).

Older people may define themselves as old by these societal expectations or align themselves with normative behaviours and associated needs. However, the needs of the aged as determined by society may not be the same as perceived or described by the individual. Bradshaw (1972) describes four aspects of need when contemplating health and social care provision for older people; normative, comparative, felt and expressed. Normative needs are set against the norms of society and determined by the criteria as established by the relevant UK government departments. Comparative need in this context would suggest that older people are needier in terms of their biopsychosocial and economic status as pensioners (DH 2003). These categories of need contrast markedly with the individual's *felt* or *expressed* need. People have their own perspective on their needs which may not be the same as what they say they need. However, because of the subjective nature of felt or expressed need, these

needs should not be considered as merely aspirational but reasonable and necessary to support and maintain independence (DH 2010).

1.2.2 Specialist Palliative Care in the UK

Specialist palliative care has its origins in the hospice movement with objectives to manage the symptom experience and enhance quality of life for those dying with cancer. The care needs of people dying with cancer were championed by Dame Cicely Saunders, founder of the modern hospice movement (Hearn & Higginson 1998). Specialist palliative care teams were multi professional teams established to provide physical, psychological, social and spiritual support for people with advanced cancer or limited prognosis, usually based in hospices or hospitals.

The ageing population with increased incidence of cancer and associated co-morbidities of ageing has resulted in increasing demand for specialist palliative care services. However, despite growing evidence of patient benefit, limited funding for care provision has affected access to services (Higginson & Evans 2010, Gardiner *et al* 2011, DH 2012b, DH 2012c, DH 2012d, DH 2012e).

UK Government policy has encouraged more community based palliative care for older people. The NICE Quality Standard for End of Life Care has recently set out the requirement of health professionals to provide care, compassion, kindness and skilled application of knowledge in a person-centred way (NICE 2011). This has moved the focus of the specialist palliative care team away from the hospice or hospital to the home or care home. Increasingly community based specialist palliative care teams in the UK are providing care to those at home or in hospital (Seow *et al* 2014).

Despite the NICE standards, inequalities in care provision and funding continue in the absence of unequivocal evidence for the patient benefit of having community based specialist palliative care services for older people in particular (Cassel 2013, Lockett *et al* 2013, Gomes *et al* 2014). This problem can only increase in the future as the ageing population increases. Given this context, research into all aspects of the experience,

care and associated benefits for older people with specialist palliative care needs is necessary and vital.

1.2.3 Pain in Older People

It is questionable whether older people have a different experience of pain from younger adults which justifies any under treatment of their pain. The physiological basis for experiencing pain in an aged nervous system might suggest that older people might have a lower sensitivity to pain and thus have a higher pain threshold (Gibson & Helme 2000). Indeed, some researchers suggest that older people's general experience of pain is less than that of younger adults with similar disease progression (Cole *et al* 2010, Gibson & Lussier 2012). Decreased sensitivity to external stimuli, which has also been associated with increasing cognitive impairment due to common vascular and neurological diseases of the brain, is frequently associated with ageing (Karp *et al* 2008). However, such gross generalisations are questionable when all potential confounding factors are taken into consideration. The nature of pain experienced is not only dependent on age but is affected by the type and stage of tumour, previous experience, the context and current environment in which it occurs (Schiavenato & Craig 2010). Additionally, old age may mean increasing prevalence of other painful co-morbidities and polypharmacology.

In practice however, older people may be subject to restrictions on the types and amounts of analgesia which can be provided (Abdulla *et al* 2013). This constraint is frequently justified by other disease processes, which are more frequent in but not common to all older people, such as reduced renal function (Mercadante *et al* 2006). The susceptibility to increased effect and chronic toxicity is associated with decreasing renal function is associated with ageing but not exclusive to older people. Thus, the increasing health and longevity of the ageing population, in the industrialised world, has led to a separation between physiological and chronological age with associated stratified or restricted analgesia regimens.

Older people may experience pain; however, the experience of pain is not unique to any particular group of the population but is unique to the experiencing individual. The ubiquitous nature of pain has made it difficult to conceptualise. Indeed, pain has been described as:

'...whatever the experiencing person says it is, existing whenever the experiencing person says it does' (McCaffrey 1979:7).

Furthermore, the International Association for the Study of Pain (IASP) has accepted the following definition:

'...an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage' (Merskey & Bogduk 1994:210).

Both these definitions of pain rely on the ability of an individual to express pain verbally and acknowledge the subjective nature of the experience of pain. Thus, definitions of pain may be limited by the ability or willingness of the patient to make a verbal report and the ability of the health professional to understand and interpret appropriately.

Pain is very common in older people; with almost 5 million people aged 65 and older experiencing pain or discomfort in the UK (Kumar & Allcock 2008). Indeed, pain in older people is an acknowledged physical and therapeutic problem. Furthermore, there is evidence that sensory ability may decline increasingly with advancing age (Gagliese & Farrell 2005). However, it is not established whether this changing sensory ability may result in a predisposition to either increased or decreased pain sensitivity, as much of the neurological data is modelled on animal studies. Thus, there is no clear biological rationale for the changing pain experience with increasing age. Similarly, the biopsychosocial changes are not fully understood (Gibson & Weiner 2005, Hadjistavropoulos *et al* 2011).

Older people may be perceived by health care professionals as exaggerating their pain experience despite the acknowledged deleterious effect of pain on activities of living (Blomqvist 2003, Reyes-Gibby *et al* 2003, Chodosh *et al* 2004). This negative attitude towards older people and pain may relate to the popular myth that pain is a normal consequence of ageing (Davis *et al* 2002, Gibson & Weiner 2005, Gignac *et al* 2006). Furthermore, there is growing epidemiological evidence that the prevalence of pain increases with age which justifies more research into the experience of older people in pain (Helme & Gibson 2001, Jakobsson *et al* 2003, Gibson 2006, Cole *et al* 2010). Moreover, pain is debilitating to the individual and costly for society but is not an inevitable part of ageing (Schofield *et al* 2011, Yeziarski *et al* 2012).

Assessment and understanding of the patient's pain experience is the foundation of good pain management and pain relief. However, pain is subjective and may be difficult to articulate and assess objectively. Moreover, most assessment tools and measurement scales are based on ordinal and interval data, or are word based (Scott & Huskisson 1976, Wong & Baker 1988, Price *et al* 1994, Katz & Melzack 1999, Herr *et al* 2004, Schofield *et al* 2006, Gregory & Richardson 2014). These are often linear or one-dimensional because they measure only one aspect of the experience such as intensity. However, some pain assessment tools are designed to measure more than one aspect of the pain experience and combine simple numeric and word based strategies. These are known as multi-dimensional tools. Multidimensional tools may be more useful for assessing the complex experience of cancer pain such as:

- The Abbey Scale (Abbey *et al* 2004, Schofield 2014).
- Modified McGill Pain Questionnaire (Turk & Okifuji 1999, Gauthier *et al* 2014)
- The Brief Pain Inventory (Keller *et al* 2004, Atkinson *et al* 2011).

None of these have been developed or validated for use in assessing cognitively able older people. Moreover there is no consensus for use of any particular pain assessment strategy or tool in clinical practice whether hospital or community.

Expert consensus remains the primary source of guidance for pain assessment in older people in the UK and Europe (Royal College of Physicians *et al* 2007, Hadjistavropoulos *et al* 2007). Pain assessment should always be based on the individual's own description of their pain experience or 'self report'. However in the clinical environment the assessment is usually based on a combination of the 'self report', the observed physiological process or event which has caused the pain, and the observed behavioural response of the individual. Therefore empathy, understanding visual and non verbal cues of suffering are all important to assess pain (Ferrell *et al* 1995, Yamada & Decety 2009).

Clearly, the amount and effects of pain in older people is a contentious and unresolved topic. No other studies to date have explored the subjective experiences of older people with cancer pain whilst accessing specialist palliative care.

1.3 Philosophical and Theoretical Framework

The goal of all health care research is to generate knowledge which may enhance health care (Burns & Grove 2005). Health care has a substantial history of clinical research which is designed to be generalisable. There are many aspects of health care which benefit from objective and systematic observations related to health care interventions. Indeed, having objective, generalisable data may be useful for a large group or population; but it is individuals who experience care. The experience of health care for the individual may not reflect the expectations of health care when compared with an average recipient in a large clinical trial or study.

Modern health care can enhance and improve lives (DH 2000, DH 2000a, DH 2000b). However, only the person who lives with illness can know whether life has improved. The experience of one may differ from another and there may be no collective or generalisable experience. This is particularly the reality of the subjective nature of both illness and pain. In this context decisions are made, about care, which are based on judgements about things which cannot be objectively measured. For example, in the assessment and management of pain the healthcare professional is frequently reliant

on guidelines, principles of care and assessment tools which, whilst useful in managing the care of many when minimum standards are required, may not always help the individual sufferer of pain. Tools may be one-dimensional and thus not able to capture the nature of living with pain.

People do not just experience pain they suffer with pain and this suffering may be manifest through their personal account of effect and expression of need. Many factors are known to affect the experience of pain but the pain may also have a considerable influence on these factors also. Moreover, the experience of cancer pain may be expressed in terms of its effects rather than in terms of pain or 'similar' words.

The antithesis of suffering is health which may be expressed as quality of life. However, quality of life measurement for the individual may not be an accurate antonym for the individual's experience of suffering and both may co-exist depending on the questioner or circumstance of enquiry. In practice there are well established measures such as the QALY (quality adjusted life score) which are designed to address closed questions about living with disease but which may not make sufficient distinction between circumstances nor have the discriminatory ability to provide a true picture of experience (Fitzpatrick *et al* 1992).

The distinction between research about populations and the needs of individuals has resonance with the perceived subjective objective divide between nursing and medical research (Hammersley 1992). However, care and its experience are not easily distinguishable for the individual service user as endorsed by the findings of the recent Mid Staffordshire Public Inquiry about failings in care (Francis 2013). In response to this and previous reports of poor care and services, the concept of person centred care, where the health care service user is central, has become one of the NHS core principles (DH 2013³)

³The NHS Constitution (2013)
<http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/2013/handbook-to-the-nhs-constitution.pdf>

Person centred care manifested through independence and autonomy are desirable goals for both medical and social policy (DH 2005, Fine & Glendenning 2005, DH 2006). Older people also need to feel in control in order to manage their needs and stay independent (Wilken *et al* 2002). Towards achieving these goals much has been written about person centred care and its importance in ensuring that the needs of the individual are respected (McCormack 2001, 2003, Clarke *et al* 2003, Nolan *et al* 2004, McCance *et al* 2011). Moreover, 'person centred care' might be considered synonymous with 'quality care'. However, application of the theory and philosophy of person centredness into practice is not without difficulty because of the practical issues of funding and the bureaucracy of outcome measurement (McCormack & McCance 2006, Nolan *et al* 2006). In its application, the concept of person-centred care is unavoidably linked with concepts of caring and therapeutic relationships and has been offered as a conceptual framework (Appendix I) (McCormack 2003, McCormack & McCance 2006).

Recently, integrated health and social care for older people has been championed by the Joseph Rowntree Foundation (Granville *et al* 2014). McCormack advocates that the 'caring' of person-centred care is a human trait, a moral imperative, and interpersonal interaction imbued with compassion but primarily underscored with therapeutic intervention (McCormack & McCance 2010:23). Similarly, holistic care is an approach to health care which transcends the biopsychosocial model of care to encompass all the aspects of life and experience which affect the individual (NICE 2011). Person centred care and holistic centred care approaches encourage and support an understanding of the whole experience of illness, one which is greater than the physical and observable aspects of illness, and which is inclusive of personal experience.

Illness and disease are terms generally given as synonymous in definition but which can be different conceptually and have different perspectives depending on whether they are described by the experiencing person or an outsider. In anthropological terms disease may cause illness but some diseases may be asymptomatic. Illness implies a continuum and a proportion in a life world which is distinct from the constancy of

disease. Illness also relates to the socio-cultural environment in which disease is experienced. Whereas disease, as the biological or physiological problem, is presented as the outsider's perspective, is diagnostic, categorical and fixed. People experience illness whilst living with disease and health care delivery is largely based on a biomedical model of diagnosis and treatment (Conrad & Barker 2010). Fully managing the illness implies a holistic view which is more than simply understanding the mechanics of disease and appreciates the experience of living and adapting to the changes which disease effects.

To develop an understanding of the unique personal experiences and needs of older people with cancer pain Interpretative Phenomenological Analysis (IPA) was used to explore lived experiences. Application of the theoretical principles of phenomenology through IPA enabled some illumination of the experience of older people with cancer pain.

1.4 Assumptions

More detail about the IPA methodology is given in chapter 3. However, it is essential, in any study which utilises phenomenology or IPA, that the researcher identifies any assumptions, biases or preconceptions about the phenomena of interest (Langdrige 2007, Chan *et al* 2013). This is fundamental to the tenets of phenomenology, to focus on the phenomenon as it appears to the experiencing person, to 'bracket' any assumptions about what is already known. To ensure that the participant's view of the phenomenon is presented then arguably bracketing is vital to consider at the outset of a research study. The main assumptions informing this research are identified here:

- Older people are as important to society as other age groups.
- Pain is more than the observation of a third party.
- Research with anyone who is living or dying with cancer is valuable and preferable to any third party source, albeit recognising the sensitivities and ethical challenges.

- Quality of health care involves more than satisfying 'outcome measures'
- There are limited resources to support research into older people's health care needs.
- Older people with cancer and pain are likely to experience some or all of the following; suffering, dissatisfaction, poor quality of life, dissatisfaction or neglect.

These assumptions have informed the choice of topic, the formulation of research questions the epistemological position and resulting methodology.

1.5 Study Aims and Objectives

The purpose of this study was to consider how the older person constructs the experience of cancer pain and how this is informed by expectations and experiences.

With subsidiary objectives:

- To understand the experience of cancer pain in older people
- To illuminate underlying themes and contexts that may account for this experience.

1.6 Summary and Plan of Thesis

This thesis as presented is a complete report of the research study in seven chapters.

Chapter 1: The first chapter provides a brief rationale for the research, identifies the aim and objectives and the underlying assumptions.

Chapter 2: This chapter introduces the policy and context for the study. It provides an analysis of the literature related to older people's experience of cancer pain. The review highlights the limited research in this area and links the current study to other reported research in this area.

Chapter 3: This chapter introduces the philosophy which informs the study. It describes the development of a phenomenological approach inspired by Maurice Merleau-Ponty and applied using the tenets of Interpretative Phenomenological Analysis (IPA). IPA provides the methodological framework for gaining a rich deep understanding of the lived experience of cancer pain.

Chapter 4: The methods chapter provides a detailed description of the research strategies used to underpin this study. The chapter describes the population, sample, recruitment and ethical considerations for the study. The process of data collection, data analysis and methods of establishing rigor and trustworthiness are asserted.

Chapter 5: This chapter is the first of two findings chapters. This chapter presents the nine participants' experiences of cancer pain as descriptive accounts respecting the idiosyncrasy of the individual experience.

Chapter 6: This chapter is the second findings chapter. It presents the interpretative findings and major themes across cases and between participants. The major themes were 'better to be old than to be dying with cancer', 'maintaining control and independence', 'loss of Identity- grieving for a former self', 'dislike of analgesia' and 'denial of pain'.

Chapter 7: This final chapter describes and discusses the findings of the study in the context of the wider extant literature. It provides a summary of the new knowledge which this study brings to the body of knowledge about older peoples experience of cancer pain. The chapter also provides details about the methodological and procedural limitations of the study and makes some recommendations for future research and practice for older people with cancer pain.

1.9 Summary

Chapter one has introduced the research enquiry and the concept of a study which embraces the lived experiences of nine older people with cancer pain. It has summarised the content of this thesis and the next chapter will outline the policy, context and literature which supports this thesis.

Chapter 2

Literature Review

"Respect for the autonomy and dignity of the older person must underpin our approach and practice at all times. All older people have the right to a health and social care assessment and should have access to treatments and care based on need, without an age-defined restriction to services"

(British Geriatrics Society 2013: 11)

2.1 Introduction

The focus of this study is to explore older people's experience of having pain whilst living with advanced cancer and in receipt of palliative care. The aim of this chapter is to establish a baseline for the research by i) considering existing knowledge and research which addresses the broad area of the research question and ii) identifying gaps in existing knowledge. It will situate the research focus within the context of older people's health care needs whilst living with pain and cancer and present a comprehensive understanding of the current state of knowledge about the topic.

The chapter is structured in two parts. The first section introduces the context of the global ageing population and supporting data which relates this in context to the study topic. It also considers the national and policy guidance and the specific issues relating to survivorship and palliative care for older people with cancer. The second section will consider older people's cancer pain experience from the perspective of service users. The service user perspective is summarised in the form of a critical review of available literature about older people's experience of living with cancer and pain. This section also develops the notion of this study's unique contribution to the wider academic body of knowledge in this area.

2.2. Section One. Context and Policy

2.2.1 Demographic data

The global burden of cancer is significant and increasing. According to United Nations data, the incidence of cancer, for both developed and developing countries, is predicted to increase by up to 75% as their populations develop, age and increase (UN 2009). Also, in many industrialised countries there is concern about the increasing proportion of GDP⁴ and healthcare resources required for the aged (Wittenberg *et al* 2001, Pritchard & Wallace 2011). The number of people worldwide aged 60 or older is anticipated to triple by 2050 to 2 billion with a corresponding increase in cancer incidence (UN 2009). Cancer incidence in the ageing UK population is similarly increasing. About 1.8 million people in the UK are living with cancer, this number is expected to be 3 million by 2030 (DH 2013). UK cancer incidence is estimated at 431 per 100,000 men and 375 per 100,000 women (ONS 2012a). However, approximately two thirds (63%) of all these cancers are diagnosed in people aged 65 and over and more than a third (36%) are diagnosed in the oldest old (aged 75 and over) (ONS 2012a). This reflects a massive demographic shift towards an older population with increasing occurrence of cancers.

An estimated 75% of people who have had a cancer diagnosis will experience pain resulting from the cancer or the treatment (van den Beuken-van Everdingen 2007). Improved survival rates may be accompanied by pain caused by the side effects of surgery, chemotherapy, radiotherapy and other curative or palliative interventions (Aziz & Rowland 2003). Cancer related pain has been noted as contributing to fatigue, impaired function and as affecting psychosocial factors of health, such as emotional distress and mental health problems (Carr *et al* 2004). In addition, the stress and worry of a cancer diagnosis is often accompanied by anxieties about the treatments and the physical demands that will be placed on the person with cancer, their families and

⁴ GDP or Gross Domestic Product, is an internationally agreed economic measure of a country's wealth.

carers. Older people may experience other co-morbidities which render them more likely to experience pain, and psychosocial distress, than younger people (Jakobsson *et al* 2003, Landi *et al* 2005, Leong *et al* 2007, Blyth *et al* 2008).

The extent and nature of the problem of pain in older people with cancer is largely unexplored though estimates suggest it may be sizeable (Royal College of Physicians *et al* 2007, Hadjistavropoulos *et al* 2007, IASP 2008). In a large recent European study (n= 5084) of people of all ages with all types and stages of cancer, older people were noted as receiving sub-optimal pain management (Breivik *et al* 2009). In smaller studies, pain has been noted in up to two thirds of older adults with advanced cancer, with many receiving inadequate pain relief (Fineberg *et al* 2006, Zyczkowska *et al* 2007).

Furthermore, it has been observed that older people with cancer do not always have access to specialist cancer or palliative services (Cleeland *et al* 1994, Bernabei *et al* 1998, Cleeland 1998, Burt & Raine 2004, Froggatt & Payne 2006, Duncan *et al* 2008). Indeed, older people only have access to a generic provision of care, which is largely informed by studies of younger adults, and therefore have to fit in with existing services (DH 2007).

There are many possible contributory factors to why there is little data about older people with cancer pain.

- First, the majority of studies of cancer pain have excluded those aged 65 and older (Bernabei *et al* 1998, Cleeland 1998, Balducci 2003, Goudas *et al* 2005). Older people have largely been absent from cancer and end of life research (Bugeja *et al* 1997, Seymour *et al* 2002, Avis & Deimling 2008, Breivik *et al* 2009).
- Second, older people have been noted to under-report their pain experience, particularly if the older person is cognitively impaired (Bernabei *et al* 1998).
- Third, the complex and subjective nature of pain experience makes consensus, about measuring pain and its effects, a considerable challenge for researchers. Indeed, many symptoms experienced by those with cancer are also open to

interpretation and consideration from more than one level or perspective (Richer & Ezer 2000, Tritter & Calnan 2002).

- Finally, the presence of existing painful comorbidities and the painful nature of diagnostic procedures, treatment or ongoing management of cancer may be additional and confounding factors to consider (Perkins & Kehlet 2000, Jung *et al* 2003, Maguire *et al* 2006, Burton 2007, Avis & Deimling 2008:3520). Moreover, the side effects of cancer and its treatment are likely to be compounded because of chronic comorbidities and the natural ageing process (Adams *et al* 2004, Ferlay 2007). Thus, the scale of the current problem of cancer pain and suffering, for older people is likely to be significant.

The health care needs of older people are complex and challenging and older people with cancer are more likely to become frail and vulnerable (Mohile *et al* 2009). Indeed, this increasingly aged population presents a significant demographic challenge for society and health care provision, as old age is correlated with increasing illness and inequalities of health care provision for the aged (Allmark *et al* 2010). This is important as older people are proportionately the greatest users of health care services in the UK (HES 2010).

2.2.2 Role of the organisation & the policy context

The health and social care needs of older people have been acknowledged by the UK Government largely focusing on the economic challenges which this growing population may bring. To address these anticipated challenges, the UK Department of Health developed the National Service Framework (NSF) for Older People (DH 2001). Recommendations in the NSF included that older people should be treated with dignity and respect and advocated 'person-centred care'. Subsequently, a greater focus has been placed on health promotion and maintaining health and support for independent living (DH 2004a).

In an attempt to provide for and meet the health care needs of the UK's ageing population, the Department of Health launched the 'Dignity in Care Campaign' (DH 2006). This has been further acknowledged in the Healthcare Commission's report 'Caring for Dignity' and the UK Government's Joint Committee on Human Rights report 'The Human Rights of Older People on Healthcare' (Healthcare Commission 2007, House of Lords House of Commons Joint Committee on Human Rights 2007). This is supported in the anti-ageist section of the anti-discriminatory legislation of the Equality Act (2010). Respect and dignity for all, regardless of age, now comprises one of six core NHS values. These are outlined within the NHS Constitution (DH 2012a) and reinforced, specifically for older people with cancer, in a Macmillan Cancer Support, AgeUK and Department of Health collaboration in 2012 ⁵.

Despite all these initiatives a recent report suggests that there are many avoidable deaths in the 'over 75s' because age, rather than clinical need, is a determinant of access to cancer services in the UK (Devane 2014). Health care resources are limited and, despite the 2010 Antidiscrimination Act, ageism continues (Fernando *et al* 2011). The recent UK Department of Health's National Awareness and Early Diagnosis initiative specifically excluded those aged over 75 years from routine screening for common cancers (DH 2011). Moreover, according to a UK survey of health care providers, commissioned by Macmillan Cancer Support (2012), people over 75 years of age with cancer do not get the same treatment options as younger adults. The resulting under-treatment of cancers in this age group has been estimated to contribute to some 14,000 annual cancer deaths in the UK (Moller *et al* 2011). In those aged under 75 years cancer mortality rates are notably better than for those aged over 75 (National Cancer Intelligence Network 2010, 2014). Clearly, with the UK population ageing, prioritising older people's care needs is becoming increasingly challenging.

⁵ . Macmillan Cancer Support, DH & AgeUK (2012) Cancer Services Coming of Age: Learning from the Improving Cancer Treatment Assessment and Support for Older People Project https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213205/DH_Macmillan_Age-UK_Report_Final.pdf

2.2.3 Older People Living with and Beyond a Cancer Diagnosis

Despite the problem of late diagnosis, improvements in the treatment of cancers have resulted in improved rates of survival for older people (Devane 2009). Cancer survivorship, in an ageing population, has important implications for clinical practice. The effects of the cancer and its treatment may result in chronic health problems, including pain, many years after treatment for the cancer has ended (Alfano & Rowland 2006, Deimling *et al* 2006). The publication of the National Cancer Survivorship Initiative (NCSI) demonstrated a policy commitment by the UK Government and Macmillan Cancer Support to recognise the specific psychological, physical and social issues resulting from having a cancer diagnosis and to support research into the needs of all people living with and beyond cancer (DH 2011, DH *et al* 2013).

The UK NHS Cancer Plan (DH 2000) envisaged a patient centred service and has raised expectations for symptom management and treatment and this is reinforced in the UK Dignity in Care paper (DH 2006). Both initiatives endorse the imperative that all older people are treated with dignity when using health and social care services. The UK End of Life Strategy has also recognised the increasingly aged population and the corresponding increase in cancer incidence (DH 2008). The strategy represents a commitment by the UK Department of Health to improve care for all by considering workforce training and service development to improve end of life care. However this is a global issue not just a UK one with an increasingly aged world population (Breivik *et al* 2009)

However, for those with palliative care needs, the long awaited End of Life Care Strategy for England has made little mention of older people (DH 2008). Similarly, the Gold Standards Framework and the Liverpool Care Pathway, which clearly endorsed the importance of adequate assessment and pain relief for cancer, made scant reference to the needs of older people (Thomas & Free 2006, Ellershaw 2007). Indeed, increasing concerns such as health inequalities and poor provision of care for older people with cancer were noted in the 2007 Cancer Reform Strategy (DH 2007). Sadly,

this was recently reiterated in the findings of the 2011 Ombudsman's Report 'Care and compassion' which raised concerns that older people do not get adequate or appropriate services and identified that older people need better care and care which is suited to their needs (Parliamentary and Health Services Ombudsman 2011).

The under-treatment of pain in older people, or any group of people, is unethical and unacceptable. In particular pain in older people may have a deleterious effect on their wellbeing and independence. Inadequately managed pain is known to have detrimental effects on quality of life and activities of daily living (Portenoy & Lesage 1999, Lin *et al* 2003, Deandrea *et al* 2014). Moreover, the individual experience of cancer pain is unique and complex because of its multifactorial nature and because of the potential for association of worsening pain with progression of disease (Turk & Fernandez 1990). Also, there may be a popular perception that experiences, such as cancer and pain in old age, are inevitable and thereby worth less resourcing within research and consequently within health care provision (Biggs & Powell 2001). The right to receive adequate pain relief is a fundamental human right and declared as such by the International Association for the Study of Pain (IASP) and the World Health Organisation (WHO) (Lipman 2005, Brennan *et al* 2007). Thus older people's experience of cancer and pain is worthy of consideration.

2.3. Section Two. The health care user's perspective and ontological debate

2.3.1 Introduction to section

With regard to ageing, cancer and reported pain, it is important to appreciate and understand the unique and individual needs of older people so as to inform good practice. Effective care for older people with cancer and pain should be holistic, individualised and effective. Research and dialogue about cancer pain and its effects on daily lives are vital to understanding how to manage this problem. There are professional and lay perspectives on the disease process of cancer, having pain and being old. The health professionals perspective is informed and driven by guidance

from the various advisory and funding authorities, professional bodies and societies⁶. These guidelines and policies are largely concerned with the prevention and management of pain but are only effective if older people's pain is diagnosed or reported. Older people in particular may be reticent to report their experiences of living with pain because of expectations that pain is 'normal' in old age. If this situation is to change there must be an appreciation of all health care users as partners, in their health care and illness experience, and older people should to be encouraged to share their experiences.

2.3.2 The Experiencing Person's Perspective

A person's experience of cancer, pain or any chronic illness is complex and unique to that person. The individual's expression of that experience is equally complex and unique and therefore subject to interpretation in the context of social existence and may not be the same as is anticipated by those who provide health care. Older people are health care service users and are entitled to access to appropriate health care services which are suited to their unique needs. To emphasise this, current UK Department of Health policy and practice initiatives welcome the contribution of service users to research, design and delivery of health care services (Collins *et al* 2010). Service user involvement can be through participation in planning their own care or through more structured and organised involvement in the planning, monitoring and development of health services. However, the inclusion of older people, with cancer as partners in the planning of care services, is not evident within UK health care provision. Indeed, older people may have quite a different view of their experience of disease, priorities of care and needs from those of health care professionals.

⁶ These organisations include the National Institute for Clinical Excellence (NICE), the Department of Health (DH), the various professional statutory regulatory bodies (PSRBs), the British Pain Society, the British Geriatrics Society and the Palliative Care Society. The General Medical Council, The Nursing & Midwifery Council and The Health Professions Council, which incorporates Colleges for the various allied health professions, all have codes of conduct and variously have detailed guidance to supplement these.

2.3.3 Critical Review of Service User Perspective

To explore the existing body of knowledge about the service user perspective, a narrative literature review of available primary research was undertaken. The review included here is an updated version of an earlier review (Dunham *et al* 2013). The aim of this review was to describe and critique the evidence about the experience of older people with cancer pain and to consider how exploration of this may inform clinical practice and research. The purpose of and approaches to undertaking a review prior to completing a doctoral level study are varied and informed by the phenomenon being studied. The phenomenon of pain experience is both complex and subjective; it is also common amongst those who have cancer (Richer & Ezer 2000, Gauthier *et al* 2009). Synthesis of evidence, in the form of a narrative review, from both qualitative and quantitative research can address subjective and complex issues of experience (Mays *et al* 2005, Barnett-Page & Thomas 2009). A narrative review is also justified when there are limited numbers of diverse papers and a need to consider the available research pragmatically (Mays *et al* 2005).

The review was important to make sense of the existing concerns surrounding the expression of cancer related pain and was necessary to undertake this study. The review provided an appreciation of the terminology used to describe older people and the methodological possibilities for undertaking study in this area (Grant & Booth 2009). The objective of undertaking a literature review was to expose gaps in knowledge and to identify the main areas of dispute and uncertainty (Mayes *et al* 2001).

Search strategy

The search strategy aimed to extract suitable literature which was relevant to the phenomenon of interest, that is, older people's experience of cancer pain. Advice regarding the suitability of databases was sought from the University library technology staff. The literature was searched using the databases Medline, CINAHL, AMED, ASSIA, Psycinfo and the Cochrane Library using the key words pain, older

people, cancer and experience. These initial key words were identified from the wording of the research question. Initial scoping identified that the wording of the research question(s) reflected paradigmatic variations and approaches to the word 'experience' and affected the choice of search terms used. The MeSH⁷ (Medical Subject Headings) and Thesaurus alternatives which were considered included the following: 'Patient satisfaction', Quality of life, 'voice', Experience (life). A variety of search terms and combinations of terms were applied with differing results. However, the search term 'cancer pain' did not produce much literature hence the search term was widened to 'pain'. In addition the associated MeSH terms 'older people', 'elderly', 'elders', 'aged' and 'geriatric' were applied to the electronic databases (Fig 1). The BOOLEAN operators 'AND' and 'OR', were used to ensure maximum inclusion. The search from 1996 onwards was justified because of the World Health Organisation publication Cancer Pain Relief (WHO 1996) which reflected a global change towards a more comprehensive and holistic approach to the relief of pain as part of cancer management.

The final search was undertaken by a hand search of full text sources rather than relying solely on the filters of the databases used. The following journals were hand searched for relevant articles: Age & Ageing, European Journal of Cancer Care, Journal of Advanced Nursing, Journal of Clinical Nursing, Pain, Pain Medicine, Palliative Medicine, Progress in Palliative Care. Reference lists of relevant articles were also searched to identify related studies. The database searches and hand searches were undertaken in November 2010, September 2011, and updated in January 2015, following the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines (Moher *et al* 2009).

⁷ MeSH-available at: <http://www.nlm.nih.gov/mesh/>

Figure 1

Search strategy used for MEDLINE & CINHAL with MESH subheadings through EBSCO host		
1.	AB Older People OR Elderly OR Aged	342,468
2.	AB Cancer	608,364
3.	TX Pain	392,964
4.	1 AND 2 AND 3	1,370

After non research and duplicated papers were removed some 315 abstracts were scrutinised. At this stage articles relating to *in vitro* studies, pharmacological trials and non-cancer pain were excluded (n=175) (Fig 2). The remaining full text papers were retrieved (n=145). After further detailed scrutiny, and assessment of the methodological quality of each research paper using a checklist adapted from Hawker *et al* (2002). Eighteen papers were included in the review; this includes one further paper identified from the recent update (McPherson *et al* 2014).

Seven papers originated in the USA, five were from Sweden, two from the UK, one from Canada, one from Australia, one from Italy and one reported findings from both the USA and Israel. Five papers were described as quantitative, eight papers reported using qualitative methods and four described their work as using mixed methods. However, the presented qualitative data in the 'mixed methods' papers was minimal (Brockopp *et al* 1996, Cascinu *et al* 2003, Wijk & Grimby 2008, Gagliese *et al* 2009). The quantitative studies used a mixture of validated tools; researcher designed instruments and structured questionnaires (Table 2). The qualitative studies used different methodologies and varied in quality. Named qualitative methodologies included grounded theory, phenomenology and phenomenographic⁸ approaches. One of the studies is reported in two papers; both are included as they report different aspects of the same study (Duggleby 2000a, Duggleby 2000b).

⁸ The term 'Phenomenographic' from phenomenography, a qualitative research paradigm informed by interpretivism (Sjöström & Dahlgren 2002)

Inclusion criteria

The following inclusion criteria were applied:

- Date of publication 1996-2014 inclusive
- English language papers
- Primary research papers relating older peoples' experiences of cancer pain, incorporating the verbal report or narrative account of experience of cancer.

Quality Scoring

Quality appraisal of the studies was undertaken to consider the conduct and reporting of all the included studies using an established framework (Hawker *et al* 2002).

Application of the framework afforded an opportunity to identify any methodological or design flaws and to consider the specific strengths and weaknesses of each study, none were excluded at this stage. The quality scores⁹ assigned to each study are noted in Table 1 and were agreed during the process of research synthesis.

Research Synthesis and Theme Development

The themes and major findings from all the included studies were collated in a tabular matrix informed by Miles & Huberman's (1994) cross case analysis method. This was accompanied by repeated close reading of each of the studies from which notes and extracts were recorded against the themes and findings in the matrix. By moving between the original primary studies and the thematic table, the various descriptions, findings and interpretation of each study were thus compared, categorised and clustered to inform this critical narrative review.

2.3.4 Findings

The results of the review are presented in terms of a summary and evaluation of the literature in relation to the research aim. The evidence can be grouped into four main themes (i) personal understanding of the experience of cancer pain (ii) communication and language of the pain experience (iii) the support of caregivers and (iv) effects on life and living.

⁹ The quality scoring system devised by Hawker *et al* (2002) is noted in table 1 and in Appendix B

Figure 2

Flow Diagram showing search process (following PRISMA guidelines)

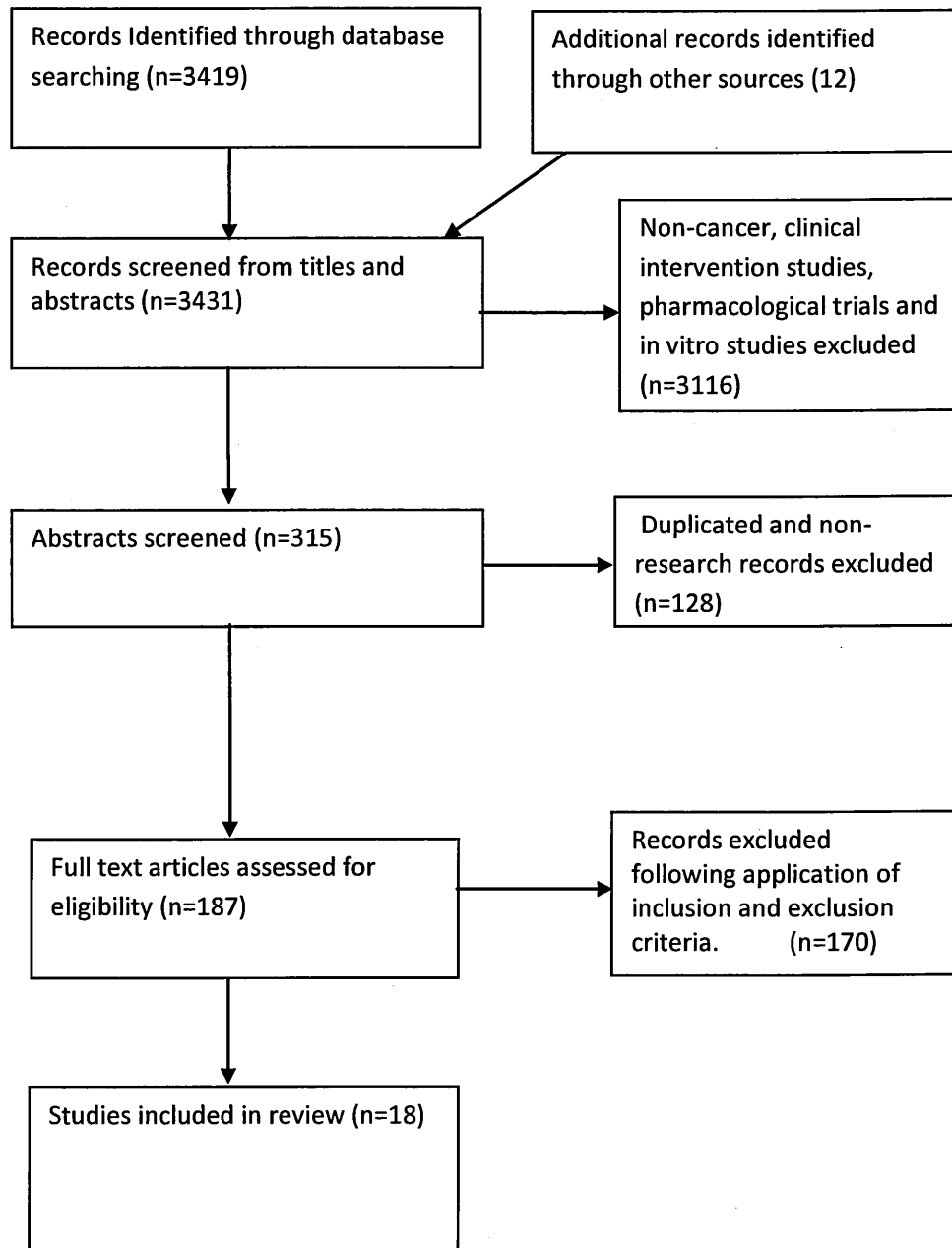


Table 1

Matrix of papers 'Older people's cancer pain experience'

Paper	Purpose	Sampling	Data collection	Data analysis	Major findings	Methodological quality and comments ¹⁰
Bennett <i>et al</i> (2009) UK, descriptive, observational study, quantitative	To examine whether older cancer patients living at home experienced poorer pain management than younger patients.	2 groups of cancer patients referred to the specialist palliative services. 58 Aged 75+ 32 Aged <65	Brief Pain Inventory, Hospital Anxiety and Depression Scale, Self-complete Leeds Assessment of Neuroathic Symptoms and Signs. Barriers Questionnaire	Descriptive statistics	There were no significant differences in findings between the two groups.	35
Bostrom <i>et al</i> (2004) Sweden, phenomenographic approach qualitative	To describe how patients with cancer related pain in palliative care setting perceived management of their pain.	Patients diagnosed with cancer, receiving care from palliative care teams. 30 participants 9<65 21>65.	Open and semi structured interviews. patients chose place of interview.	Data grouped into patterns with common themes, then grouped into categories.	Communication, planning and trust. Importance of allowing patients to discuss pain and its treatment, as patients desire to be pain free.	34
Brockopp <i>et al</i> (1996) USA, mixed, qualitative and quantitative.	To gain an understanding of hospice patients' perspective on the management of pain.	Cancer hospice patients, over 65 with no professional health care experience. 57 participants.	Investigator designed instruments and socio demographic data.	ANOVA, t-tests and descriptive statistics. Qualitative data-thematic analysis.	77% of participants felt that complaints of pain in the elderly are not taken seriously.	31

¹⁰ See methodological scoring in **Appendix B**

Matrix of papers 'Older people's cancer pain experience' cont.

Paper	Purpose	Sampling	Data collection	Data analysis	Major findings	Methodological Quality & Comments
Cascinu <i>et al</i> (2003) Italy, quantitative and qualitative.	To assess the quality of pain management in hospitalised cancer.	Two groups those aged 21-50 and those aged 51-79. 120 participants.	Interview MPQ Nursing Care evaluation Pain management evaluation	Descriptive statistics.	Pain relief in hospitals for older cancer patients unsatisfactory.	33
Cohen <i>et al</i> (2005) USA & Israel, cross-sectional. quantitative	To examine the cancer pain experience of patients 65 years and older in America and Israel.	Convenience sample from radiation and oncology outpatient units of two hospitals in Israel and USA.	Six instruments administered as a research questionnaire. Medical history data collected by research assistant.	Descriptive statistics, t-tests, chi squared, bi-variate analysis and multiple regression analysis,	Differences in pain experience statistically different between Israeli and US groups. Importance of cultural and religious influences on pain experience.	29
Duggieby (2000a) USA, Qualitative, grounded theory (Oncology Nursing Forum)	To identify, describe and generate a theoretical analysis of the pain experience of elderly hospice patients with cancer.	11 participants over 65 years, with advanced cancer and receiving hospice care.	Broad, unstructured audio taped interviews in their own homes.	Constant comparative analysis and use of NUD*IST software.	Pain is suffering and has to be endured. Endurance is maintained through hope and adjusting	31

Matrix of papers 'Older people's cancer pain experience' cont.

Paper	Purpose	Sampling	Data collection	Data analysis	Major findings	Methodological Quality and Comments
Duggleby (2000b) USA, Qualitative research design. (American Journal of Hospice & Palliative Care)	To identify and describe the pain experience in this population.	Non probability, convenience, purposive. 11 participants aged 65+ with advanced cancer, receiving hospice care, English speaking & consenting to participate.	Taped interviews in their own homes. Demographic data and medical data.	Constant comparative analysis. Cross coding and categorisation of data.	Hierarchy of pain, psychological and physical. Psychological worst pain. Immediate reality of pain, security and dealing with pain.	30
Gagliese <i>et al</i> (2009) USA, Mixed methods.	To explore age-related patterns in adaptation to chronic cancer-related pain in younger and older patients.	Consecutive attendees at a cancer outpatients clinic. 15<60 17≥60	Questionnaire and taped semi structured interviews at the clinic	Descriptive statistics. Constant comparative analysis.	Different adaptations to pain between older and younger participants. Younger people were 'waiting to live' and the older people were 'living despite pain'.	35
Larsson & Wijk (2007) Sweden, Descriptive Exploratory	To enhance the understanding of how patients experience their pain management at the end of life.	Patients with cancer disease at the end of life treated with and intrathecal pump. Three patients aged 54,74 & 82	Tape recorded interviews in the hospital and at the participants' home.	Content analysis for patterns & themes	Three themes: The pain was dreadful, reminding the patient of the cancer and the uncertainty of the future. The need to reveal and conceal pain coexisted. The pain management and structured guideline contributed positively.	27

Matrix of papers 'Older people's cancer pain experience' cont.

Paper	Purpose	Sampling	Data collection	Data analysis	Major findings	Methodological Quality and Comments
Leydon <i>et al</i> (2003) UK, Qualitative	Provide an insight into the time between this symptom attending a healthcare provider and obtaining cancer diagnosis	Recruited through community based organisations. Aware of diagnosis. Ages 54-74. 33 people.	Semi structured telephone and face-to-face interview and focus groups.	Transcripts analysed for thematic content.	Pain and fear of death. Role of family and significant others, fear, communication, rationalisation.	34
McPherson <i>et al</i> (2014) Canada, Qualitative	To describe the roles and perceptions of olderpatients with advanced cancer in managing pain in the home setting.	Recruited through community health care services. Diagnosed with advanced cancer and experience of pain > 1 month. N= 18 (Mean age 77.7)	Semistructured interviews	Thematic analysis	Two major themes, communicating the pain and 'finding a solution'. Sub themes included, roles, identification of pain, beliefs and perspectives on the perspectives of treatment.	34
Riley-Doucet (2005) USA, descriptive, cross sectional design, Quantitative	To investigate the influence of family dyadic beliefs about the controllability of cancer-related pain on patient symptom distress caregiver burden.	Convenience sample, 81 patient-caregiver dyads. Aged 55 years and older. (Mean age 65)	Questionnaire administered in outpatient waiting room: Perception of pain controllability, Symptom distress scale.	Descriptive statistics	Congruent family/patient beliefs appear to have a positive effect on pain management experience	30

Matrix of papers 'Older people's cancer pain experience' cont.

Paper	Purpose	Sampling	Data collection	Data analysis	Major findings	Methodological Quality and Comments
Ryan (2005) USA, Phenomenologic inquiry, qualitative	To explore the lived experience and associated meaning of approaching death among older adults with advanced cancer using a phenomenologic design.	Five people over 65 purposefully selected with advanced cancer.	Taped, in depth interviews at the participants' home.	Contextual processing. Narrative – description in context.	Cancer affects more than just the physical body. Knowledge from patients experiences can inform care and enhance quality of life	34
Thomé <i>et al</i> (2003) Sweden, qualitative	To investigate the experience of older people living with cancer and the way it affects their daily life.	41 participants with cancer aged over 75 years.	Tape recorded telephone interview, semi structured.	Latent content analysis.	Living with cancer-fatigue and pain. Being aware of disease. Daily life and adapting. Affirmation or rejection from health care professionals.	31
Thomé <i>et al</i> (2004) Sweden, Hermeneutic phenomenological, qualitative	To investigate the meaning of living with cancer in older age.	Ten people aged 75 & over, diagnosis cancer, completed cancer treatment.	Interview at participants' home.	Holistic reading approach. Analysis for themes	Transition into a more or less disintegrated existence. Sudden awareness of the finiteness of life. Redefinition of one's role in life. Meeting disease and illness.	33

Matrix of papers 'Older people's cancer pain experience' cont.

Paper	Purpose	Sampling	Data collection	Data analysis	Major findings	Methodological Quality and Comments
Vogelzang <i>et al</i> (1997) USA, Survey, quantitative	To determine the prevalence, severity and impact of fatigue on cancer patients. Oh to assess the problems and impact of fatigue in cancer patients and clarify the perceptions of primary caregivers and oncologists tripart survey.	Recruited from 100,000 households. Undergone chemotherapy and/radiotherapy. 419 participants	Telephone interview	Descriptive statistics.	Younger patients more likely to report fatigue grater problem than pain. Fatigue affects the ability to cope with cancer and other symptoms including pain	28
Wijk & Grimby (2008) Sweden, Mixed methods	..about needs at the end of life aims at describing the individual reports from 30 elderly patients on their needs and their ranking of needs by degree of concern.	Thirty older people, consecutive attendees at a geriatric department with a diagnosis of cancer.	Interview, at the hospital department.	Descriptive statistics, narrative report of qualitative findings	Physical pain overshadows other needs.	30
Yates <i>et al</i> (2002) Australia, quantitative	To examine the relationship between demographic factors and pain experiences and beliefs.	Cross sectional survey utilising 114 inpatient oncology patients. 41 aged 61-74 11 aged 75+	Structured questionnaire	Descriptive statistics	Older people experience more severe pain, willing to tolerate pain but perceive less control.	33

Personal understanding of the experience of cancer pain

Aspects of the pain experience which were described by the participants were considered by eleven studies (Brockopp *et al* 1996, Vogelzang *et al* 1997, Duggleby 2000b, Leydon *et al* 2003, Thomé 2003, Bostrom *et al* 2004, Riley-Doucet 2005, Ryan 2005, Larsson & Wijk 2007, Wijk & Grimby 2008, McPherson *et al* 2014).

Bostrom *et al* (2004) considered how 21 older people with cancer perceived management of their pain in a Swedish hospice; the researchers found that the older people associated worsening pain with disease progression. In particular the fear of the pain was contrasted with fear of the side effects of the analgesia and note was made of the way experiencing pain contributed to feelings of fatigue (Bostrom *et al* 2004). Feeling helpless in relation to the pain experience was a common theme in a study in a US hospice (Duggleby 2000b). Duggleby (2000b) conducted interviews with 11 participants aged over 65 years and found that adjustment to the experience of pain was challenging. The experience of pain was associated with anxieties about death and dying and also perceived as part of living with cancer in a phenomenological study of 10 Swedish older people (Thomé *et al* 2004). Five other studies noted similar anxieties of and fears about the pain and the associated disease progression or side effects of treatments for the pain (Brockopp *et al* 1996, Leydon *et al* 2003, Thomé 2003, Larsson & Wijk 2007, Wijk & Grimby 2008).

Larsson and Wijk (2007) considered the experience and effects of living with pain and cancer in a Swedish exploratory study of three older people and noted that pain reminded the participants of the cancer and an uncertain future. However, in contrast with the earlier fatalistic perspective, the researchers found that these older people, at some point in the progression of the cancer, were able to transcend the pain experience with a new perspective on life (Larsson & Wijk 2007). Similarly, Ryan (2005) considered the unique perspective and contextual meaning of the experience of approaching death for five older people with advanced cancer. The similarities in symptoms, particularly suffering associated with pain, were noted (Ryan 2005).

Three studies contrasted the older people and their lay or professional caregiver's perspectives on the experience of cancer pain (Vogelzang *et al* 1997, Riley-Doucet 2005, McPherson *et al* 2014). Riley-Doucet found that 162 US people's beliefs and experiences about pain were congruent with their family carer; however, the influencing and confounding effect of administering a questionnaire to the older person in the presence of their carer was not explored. Vogelzang *et al* (1997) contrasted priorities of care between older people and their professional caregivers. The health professionals had significantly different priorities of care from their clients and clearly misunderstood the individual's or carer's report of symptoms. In McPherson's (2014) study the 15 family caregivers interviewed were more likely to think that pain was inevitable in contrast with the 20 older people who were slightly more optimistic about their pain and its successful management.

Communication between patients and health care professionals about the experience of pain.

Five papers considered communication between patients and health care professionals (Brockopp *et al* 1996, Cascinu *et al* 2003, Leydon *et al* 2003, Bostrom *et al* 2004, Cohen *et al* 2005, Larsson & Wijk 2007, McPherson *et al* 2014). Some of the studies used tools and instruments to consider pain communications, of patients and health care professionals (Table 2).

Cascinu *et al* (2003) noted that good communication between older people with cancer and their professional caregivers reduced fear of pain and increased compliance with the analgesic regime. For the majority of those who reported pain, there was poor congruence between pain scores and strength of prescribed analgesia and the oldest people reported the worst pain (Cascinu *et al* 2003). Brockopp *et al* (1996) reported similar findings in a study of 57 older Americans and their carers. The researchers acknowledged the participants' difficulties in describing their pain and the caregivers' poor understanding of the pain experience (Brockopp *et al* 1996). This poor communication between patients and caregivers was considered a contributory factor to the experience of poor pain control; however it is not entirely clear how this was

established from the presented data (Brockopp *et al* 1996). This is further supported by Bostrom *et al's* (2004) qualitative study of 21 older people. Bostrom *et al* (2004) found that older people valued being allowed the opportunity to talk and being believed by the health care professional, and noted that feelings of trust improved cooperation and participation in care. The older people's limited knowledge about different treatment strategies was apparently influenced by the health professionals' poor communication skills. Furthermore, there was an apparent disparity between the older person's perception of pain and the professional's interpretation of the pain (Bostrom *et al* 2004).

In contrast, McPherson *et al* (2014) noted the occasional reluctance of some of the participants to share information regarding their pain with either health care professionals or their family carers. Some of the participants did not want to 'bother' people with their pain, or they wanted to protect their family members from sharing in their pain and distress.

Table 2

	Pain Assessment ¹¹		Other	
Bennett <i>et al</i> (2009)	BPI	S-LANSS	HADS BQ	EuroQual Thermometer
Brockopp <i>et al</i> (1996)	Investigator designed and validated instruments		DDQ	
Cascinu <i>et al</i> (2003)	MPQ IPM	PPI	HADS	Nursing Care Evaluation Questionnaire
Cohen <i>et al</i> (2005)	BPI	PPQK	Medical history data SOC-13	SWB DDQ
Gagliese <i>et al</i> (2009)	BPI		SOMC test CCI	KPS
Riley-Doucet (2005)	PPC		DDQ SDS	SCBI
Vogelzang <i>et al</i> (1997)	Telephone interview		DDQ	
Wijk & Grimby (2008)	Structured questionnaire		-	-
Yates <i>et al</i> (2002)	64-Item questionnaire		-	-

¹¹ Instruments Used: Brief Pain Inventory; BPI, Hospital Anxiety and Depression Scale; HADS, Self-complete Leeds Assessment of Neuropathic Symptoms and Signs; SOMC Test, Short Orientation-Memory-Concentration Test; CCI, Charlson Comorbidity Index; KPS, Karnofsky Performance Status; S-LANSS, Self-related health state; EuroQual Thermometer, Barriers Questionnaire; BQ, McGill Pain Questionnaire; MPQ, Present Pain intensity Scale; PPI, Hospital Anxiety and Depression Scale; HADS, Index of Pain Management; IPM, Patient Pain Questionnaire Knowledge Subscale; PPQK, Sense of Coherence Scale; SOC-13, Spiritual Well-Being Scale; SWB, Demographic Data Questionnaire; DDQ, Perception of pain controllability; PPC, Symptom distress scale; SDS.

Cultural differences in the communication and expression of the cancer pain experience were considered by Cohen *et al* (2005). The researchers interviewed people, aged over 60 years, in hospital oncology outpatient departments in both the USA and Israel. The Israeli patients (n=39) experienced worse pain and pain interference¹² with daily life than the American patients (n=60) when analysed for variance ($p < 0.001$) and the worst pain was experienced by the oldest individuals (Cohen *et al* 2005). Potential explanations for these differences included that these were relatively small cohorts from two different populations and cultures on different continents and the Israeli older people had worse knowledge and attitudes related to pain management.

Communication of pain was used to validate the experience of cancer at diagnosis and as the disease progressed (Leydon *et al* 2003). In Leydon *et al's* (2003) UK study, older people were interviewed retrospectively to examine symptoms and experiences associated with cancer diagnosis. Pain was noted as one of those identifying symptoms which led to seeking attendance at the GP's surgery. However, some of those interviewed were fearful of communicating their pain experience because this might indicate a worsening prognosis (Leydon *et al* 2003). Similarly, Larsson & Wijk (2007) in their in-depth case study found that the expression of the experience of pain and its worsening state was perceived as confirming the disease progression and worsening prognosis. Disclosing the pain experience was presented as having either negative or positive consequences. Expressing pain to nurses or other health professionals was perceived as supportive when the result was reducing or removing the pain (Larsson & Wijk 2007).

The language of pain, meaning and experience of living with cancer were explored by Thomé *et al* (2003) in a qualitative study of 41 Swedish older people. Symptoms, including pain, were described using similar pain metaphors leading to 'cancer symptom confusion' (Thomé *et al* 2003). For some of those interviewed the cancer and

¹² Thomas E. Peat G. Harris L. Wilkie R. Croft P.R. (2010) The prevalence of pain and pain interference in a general population of older adults: cross-sectional findings from the North Staffordshire Osteoarthritis Project (NorStOP) *Pain* 110: 361-368

its symptoms were perceived as secondary to their age. Duggleby (2000b) cited many individual descriptions of experiences of cancer pain including use of words such as *suffering, soreness, hurt* and *aching all over* to describe the pain. Thomé *et al* (2004) interviewed 10 Swedish older people with cancer, seven women and three men, in their own homes using a hermeneutic phenomenological method. Pain was described with other coexisting physical symptoms. These symptoms were frequently described in pain terms for apparent emphasis, for example, alopecia was described as *painful* and the word *excruciating* was used repeatedly. Interactions with health professionals were considered as either *supporting confirming* or *unsympathetic* to older people's cancer pain experience (Thomé *et al* 2004). Thomé's study noted the meaning of the older people's lived experience of having illness, cancer and pain as a turning point in old age and a point for redefinition of self.

In Ryan's study the older people interviewed related the importance of using appropriate words to describe pain (Ryan 2005). If communication between the older person and health care professional was ineffective this contributed to feelings of loss and of self-respect. The researcher suggested that an individualised personal approach to older people's assessment through *authentic listening* and *genuine concern* should be integral to effective, appropriate care planning (Ryan 2005).

Yates *et al* (2002) reported the reluctance of some people to report their pain and noted that there were significant age differences ($p=0.04$) in reported pain severity between 114 younger and older cancer patients recruited from four Australian hospitals. The older people experienced pain of a higher severity than the younger ones but were less willing to express their pain or accept treatment for the pain, perhaps reflecting attitudes of stoicism and fatalism (Yates *et al* 2002).

The support of caregivers

The support of caregivers and mutually trusting relationships were considered essential for ensuring the rapport which supports appropriate effective care. Ten studies identified this as a significant concern of older people with cancer pain

(Brockopp *et al* 1996, Duggleby 2000a, Bostrom *et al* 2004, Leydon *et al* 2003, Thomé *et al* 2003, Thomé *et al* 2004, Riley-Doucet 2005, Ryan 2005, Larsson & Wijk 2007, Bennett *et al* 2009).

Participants in Brockopp *et al*'s (1996) study, who were invited to comment about experienced or observed pain, acknowledged the importance of a supportive relationship with their caregivers. Pain was the most distressing symptom for caregivers to observe, however, the expression of pain was not always taken seriously by health care professionals or carers (Brockopp *et al* 1996). Duggleby (2000a) noted the importance of caring relationships between older people and health care providers. Emphasis was made on the development of a supportive and encouraging role which recognises the significance of pain (Duggleby 2000a). Similarly, Bennett's UK observational study of younger and older people found that participants appreciated support from health care professionals, with three quarters noting that they had recent contact with specialist community nurses (Bennett *et al* 2009). These findings are consistent with the need for mutually trusting relationships identified by Leydon *et al* (2003). Ryan (2005) and Larsson & Wijk (2007) also identified a desire for kindness, the need for a supportive atmosphere which recognised individuality, and the need for confirmation.

Active involvement in care was noted as being important for older people with cancer pain by Bostrom *et al* (2004). Similarly, Thomé found that it was important to have an affirming relationship with health professionals and for the older people to be involved in decision making (Thomé *et al* 2003). Despite this need, in Thomé's later study the older people found that pain could intrude on their relationships with health care professionals (Thomé *et al* 2004).

Clearly, people need to be believed and shown empathy by the health professionals supporting their care. Riley-Doucet (2005) considered the beliefs of US older people and their carers attending a cancer clinic about the cancer pain, its controllability and their ability to cope. She found that if there were congruent beliefs about pain and pain controllability between the older person and their caregiver then this relationship

was supportive and promoted more positive pain outcomes (86%; $p < 0.02$). These findings contrast with those of Brockopp *et al* (1996) who found that 77% of participants felt their complaints of pain were not taken seriously.

The effects of pain on life and living

Many references were made to the effects on life and activities of living with cancer pain. However, these varied from clearly focused questions in the quantitative studies to more implicit statements from participants in the qualitative studies. Comments and effects on life and living are noted here from eight of the included studies (Duggleby 2000a, Duggleby 2000b, Thomé *et al* 2003, Thomé *et al* 2004, Bostrom *et al* 2004, Ryan 2005, Wijk & Grimby 2007, Gagliese *et al* 2009).

For the thirty older people with cancer interviewed by Wijk and Grimby (2007) pain affected all physical needs and experiences. Thomé *et al* (2003) investigated the experience of cancer and the effects on the daily life of 41 older people with cancer and noted the coexistence of pain and fatigue and the associated anxieties related to life and death. This finding is consistent with a US telephone survey which considered the fatigue and pain experiences of 419 cancer patients who had all recently undergone chemotherapy or radiotherapy (Vogelzang *et al* 1997). Pain was acknowledged to exert a greater effect on quality of life for the individual but for the cohort, fatigue was the greater concern (61% v 19%) (Vogelzang *et al* 1997).

Limitations and adverse effects of living with pain were similarly noted by several other studies (Thomé *et al* 2004, Ryan 2005, Larsson & Wijk 2007). These findings are consistent with the wider body of cancer literature where pain has been noted to interfere with people's independence and ability to perform normal daily activities (Bowling 2006, Leong *et al* 2007, Shega *et al* 2010).

In contrast, Bostrom *et al*'s (2004) participants noted that they adjusted to living with the pain. Pain was found to affect activity but activity was a strategy for coping with pain (Bostrom *et al* 2004). Indeed, being stoic and 'not giving in' to pain was perceived as important for living (Duggleby 2000a). However, the pragmatic response of the participants was often in terms of how they had adjusted their lives to living with pain.

Older people also felt their world was redefined by pain (Duggleby 2000a). When Gagliese *et al* (2009) explored age related patterns in adaptation to cancer pain; the prominent theme from the 17 older people interviewed was living despite having pain (Gagliese *et al* 2009).

2.3.5 Discussion

The most significant finding of this review is that there is scant research in this area; this makes it difficult to draw any specific and generalisable conclusions about older people's cancer pain. In addition there are a number of factors which limit the synthesis of findings. These factors include the varied aims and methodologies applied to consider the pain experiences of older people. Furthermore, the varied settings for the studies, the cultural influences and the context of interviewing, all may have influenced the findings making interpretations and generalisations difficult.

The larger quantitative studies, considering older and younger people's experiences, have a stronger empirical base for their findings but present different conclusions. The findings are unique and peculiar to each study. For example, Bennett's UK study of cancer pain in the community setting stands alone in that it did not note any difference between older and younger people's cancer pain experiences (Bennett *et al* 2009). However, the pain ratings used may not have adequately reflected the unique and personal experiences of pain and the focus on a discrete UK population may have limited the generalisability of these findings.

Some of the apparent variations in findings between these larger studies may also reflect the variety of health care systems and expectations of health care provision in different countries despite the common concern to address the needs of older people with cancer pain. Australian older people described worse experiences of cancer pain but were more willing to tolerate pain (Yates *et al* 2002). Yet, Cascinu found Italian older people interviewed had higher pain scores but all ages experienced suboptimal analgesia (Cascinu *et al* 2003). And, in Gagliese's US mixed methods study, older people described different adaptations to pain in contrast to scoring similarly to

younger adults when considering pain severity and interference using the Brief Pain Inventory (BPI) (Gagliese *et al* 2009). It is possible that these identified differences were confounded because of sociocultural factors and the language used in the description of pain and attributed meaning.

In contrast, the smaller qualitative studies in this review made no claim for generalisation. Rather, the qualitative studies variously presented theories and observations about the nature of the pain experience, emphasising the meanings, experiences and views of the participants. However, from all the studies, a number of themes and concerns were identified but, the most commonly occurring theme was communication. Communication was identified in relation to the sharing or withholding of information related to pain. Communication of pain was also used to validate the experience of living with cancer. Consistent with others, the use of communication, and its effects on locus of control or the perceived effects of control over quality of life, with health professionals was also of concern (Zimmerman *et al* 1996, Arras *et al* 2002, Ranchor *et al* 2010).

It is apparent that the communication skills of the health professionals in these studies may have been influential on the narrative accounts of their pain experiences. This is significant for both future care provision and research as good communication and supportive relationships may enhance compliance (Williams *et al* 2007). Additionally, older people may need special consideration of the context such as environment, sensitivity and situational context to support effective communication (Thorne *et al* 2013).

Locus of control in relation to communication was also an issue in relation to participants' adaptation to living with cancer pain. The complex expressions of pain clearly reflected some of the older people's ability to cope with their pain experiences and related to their understanding of the effects of cancer. This is particularly noteworthy in the broad unstructured responses elicited in Duggleby's study (2000a). Yet, the expression of pain and illness may reflect and relate older people's inability to cope (Keefe *et al* 1999, 2003, Hughes *et al* 2009).

Clearly, good effective communication which supports assessment, planning, delivery and evaluation of care, including pain, may be beneficial (Hadjistavropoulos *et al* 2011). The differences in language and cultural expectations as noted in the review findings endorse the importance of this. Good communication skills accompanied by cultural competence are essential to address inequalities in pain and symptom management for those with cancer.

Cancer pain is complex and people have been noted to catastrophise or exaggerate the significance of the experience as a coping strategy, to demonstrate the degree of distress and need for support, further complicating its consideration (Turk & Fernandez 1990, Keefe *et al* 2003, Gauthier *et al* 2012). This is reflected in the diversity of tools and instruments identified in this review (Table 2). Another confounding factor is that whilst pain is significant it cannot be divorced from the other physical symptoms of cancer, as noted by Vogelzang *et al* (1997) who considered the coexistence of pain and fatigue. Indeed, pain metaphors may be used to express aspects of the wider symptoms of cancer. Ryan *et al* (2005) noted that pain is also informed by expectations and previous experience. How people express their experience of illness may also be informed by how they understand themselves and their world as noted by Duggleby (2000b). Thus, people may choose to live with illness or 'fight' with it (Bury 2001). Moreover, the diagnosis of cancer is likely to be disruptive but also may legitimise expression of symptoms including pain (Bury 1982).

People may further redefine themselves in context with the illness experience which may influence relationships and communication with others as noted by Thomé *et al* (2004). People in pain may feel isolated if they perceive that no one empathises with their experience or that they are not believed. Indeed, supportive relationships with health care professionals have been noted to improve compliance with treatment and adjustment to diagnosis with cancer (Butow *et al* 1996). Moreover, the support of professional and lay caregivers relies on understanding the needs of older people and developing adequate levels of rapport and empathy. Another consideration is that people may restrict their responses so as to avoid implied criticism of professional

carers and services and their responses may reflect their expectations of these rather than previous experiences.

A diagnosis of cancer may create a distinctive experience and effect a different response from that of having a chronic if painful disease (Sinding & Wiernikowski 2008). Both cancer and chronic illness may constitute a biographical disruption, in the sense that neither is part of an expected trajectory of ageing, but a diagnosis of cancer may be perceived as catastrophic (Bury 2001). Indeed, older people and some health care professionals may anticipate some experience of chronic disease as part of getting older but, for the majority, the normal trajectory of ageing does not include cancer and pain. Thus, ambiguities may exist in the illness experience, alongside the subjective pain experience, which reflect the broader ambiguities in society towards the expectations of ageing and illness.

To address the unmet needs of older people with cancer pain there must be some consensus of what their needs are. However, to establish this there first should be clarity of terms and consensus about the populations under investigation. Discussion of the different definitions of old age and ageing is clearly warranted when there is such apparent lack of consensus. Indeed, the socially constructed phenomena of old age and ageism may complicate and inform the lack of research in this area (Powell & Biggs 2003, Vincent 2007). It is also important to consider the pervasive influence of ageism. The UK the media, and many health professionals, appear to use unsubstantiated generalisations of ageing (JRF 2004). Old age is not generalisable, people experience ageing individually and not as a collective. Therefore, there should be no expectation of disease and illness as part of normal ageing.

If older people with cancer are to enjoy life in old age they should benefit from all services which actively promote their role as active agents in healthy ageing. Thus, the challenge is to ensure that older people are actively included in research studies, to involve them in informing and planning their own care and to ensure that appropriate specialist services are available.

2.3.6 Summary of section 2

- There are limited data on the unique experience of older people living with cancer pain (Dunham *et al* 2013)
- Cancer pain is a complex experience
- There is little congruence between patient, caregiver and health care professionals' reports of the cancer pain experience (Hayley 2003)
- Accounts of experiences may be complicated by relationships , emotional attachment
- The health care professionals' accounts may be complicated by 'normative' expectations
- Communication of experienced pain may be impeded by use of instruments which narrow the focus of enquiry and may not be understood by the patient
- Effective use of instruments and assessment by health care professionals is reliant on their good communication skills and thorough knowledge of the instruments or assessment strategy used
- Expression of pain validates for the sufferer the existence and advancing stage of cancer
- The older person needs to trust the health care professional and the health care professional should believe the older person
- The language of pain or 'pain words' used may vary considerably between individuals
- Using 'pain words' and the experience of cancer may be used to redefine 'self'
- Metaphors are frequently used to describe pain and other symptoms which may confuse the health care professional

2.4 Summary and rationale for current study

Despite increased prevalence in an ageing population, cancer and its symptoms are under researched issues for older people. Indeed, older people, regardless of age, need representation in health care research. The ageing population and increasing survivorship of older people with cancer provide challenges for health researchers and health care providers in both defining and meeting older people's health care needs. These challenges include understanding the extent of pain as a problem for older people with cancer, managing pain and understanding the effects and difficulties of living with cancer and pain. If the effects, on older people, of living with cancer and pain are not understood care cannot be appropriately planned. Thus, the voice of older people needs representation to establish their needs, inform their care and influence the direction of future policy and service provision. The purpose of this study is to listen to the voice of older people with cancer pain and use some of these personal experiences to better inform care and future strategies of enquiry.

Chapter 3

Philosophy & Methodology

3.1 Introduction

In chapter two it was identified that there is scant understanding and appreciation of older people's cancer pain from the perspective of the person experiencing pain. Older people themselves have infrequently been approached for their account of living with pain and cancer (Davies & Higginson 2004, Lievesley 2009). As outlined in chapter one the current study explores the experience of older people with cancer. This chapter will outline the philosophical perspective, theoretical foundations and research methodology which underpin this thesis. It will describe the philosophical stance which has informed this research, elaborating the ontology and epistemological perspectives which have influenced the qualitative approach. A case will be made that in order to gain insight into the lived experience of cancer pain a qualitative and phenomenological approach is both supplementary and complementary to the objectivist stance.

To address the philosophy or research paradigm for this study one must first consider the research question.

How do older people construct the experience of cancer pain and how is this informed by expectations and experiences?

The subsidiary objectives were:

- To understand the experience of cancer pain in older people
- To illuminate underlying themes and contexts that may account for this experience

Within the context of modern health care, the service user's perspective is an invaluable resource for the development and evaluation of health care services. This largely untapped resource can be utilised to inform care, and develop a spectrum of research strategies and paradigms (Collins *et al* 2005). However, the dominant research paradigm within health care is a positivist and objectivist one, which is fundamental to the appreciation of the disease process, but may not be the most appropriate stance to address issues of meaning and understanding of illness experience.

3.2 Research Philosophy

This section considers the philosophical stance in relation to the purpose and place of research in general and of this research in particular. The research philosophy is a belief about the way data, about a phenomenon of interest such as pain, is understood. In developing the research philosophy, assumptions about the world and the nature of experience are addressed. Before setting out the methodology it is important to consider the ontological and epistemological basis for this study in context with the research aims and objectives.

3.2.1 Ontology

What is knowledge and who owns it?

Knowledge of the experience of others is central to this study. As identified in chapter 2, older people and people with cancer are more likely to have research done *about them* from a third party perspective rather than *with them* directly (Hoban *et al* 2011, Hoban *et al* 2013).

The first objective of this study is *to understand the experience of cancer pain in older people*. Experience is far more than the quantitative measurement of pain and may be encompassed in the concepts of patient centred and holistic care. Patient centred care is an ideology which places the person at the centre of care and acknowledges the sharing of power and responsibility in a therapeutic alliance between health care

provider and patient (Mead & Bower 2000, McCormack 2001, McCance *et al* 2011). Person-centredness acknowledges that the older person is the primary authority on their pain because it is *their* pain, it belongs to *them*, and it is *their words* which describe the pain and elaborate the experience of living with the pain and cancer. One definition of qualitative research is the study of 'things in their natural setting, attempting to make sense of, or interpret (a) phenomenon in terms of the meanings people bring to them' (Denzin & Lincoln 1998:3). This definition relates to the exploration and understanding of a subjective experience, such as pain, in the context of living with cancer.

The second objective of this study is to illuminate any *underlying themes and contexts which may account for this experience*. The perception of lived experience of cancer pain may be informed by previous experiences of pain and healthcare and it is not experienced in isolation. Family members, encounters with health care professionals, carers and other contextual factors may frame the beliefs, knowledge and understanding of the experience (Wells *et al* 2003, Kimberlin *et al* 2004). Thus, knowledge of pain and its effects may be framed and informed by multiple lenses of sociocultural contexts and prior experience in addition to the diagnostic information.

What is Reality?

Appreciation of the experience of others begs the question what is the nature of reality and how is knowledge produced. Is knowledge a true representation of reality? In this regard the social sciences have been proposed as a logical continuation of the natural sciences, where human activity and experience is considered with the same objectivity, rationalism and approach. This is the view espoused by some theorists and was initially proposed by the social scientist Emile Durkheim (1895), with some current advocates (Connell & Nord 1996, Thompson 2004, Paley & Lilford 2011, Cruickshank 2012).

If all human experience is reduced to the objective and measurable, can the empiricist approach to the social sciences only apply to observable facts? The basic philosophy underpinning positivism and the 'scientific method' is that, all factual knowledge is

based on information gathered from observable experience and that any concept beyond this realm of demonstrable fact is not real (Crotty 2003). In practice, the knowledge of a phenomenon is mediated through the multiple lenses of observation and experience. Indeed, knowledge may be informed by observation of phenomena; however, knowledge of the same phenomena may also be informed and mediated by experience (Popay *et al* 1998). Thus, the knowledge and understanding of the same phenomenon may be quite separate and distinct for the observer and the observed. This separation between experience and observation, in relation to particular events or phenomena, would suggest that knowledge and reality are more complex than simple observation. And account must be taken of meaning and interaction between the observer and the observed.

3.2.2 Epistemology

This study is about the lived experiences of older people with cancer and pain. As such it is not suited to a quantitative hypothesis-driven study. Indeed, health care science has traditionally been concerned with objective and quantifiable information. Moreover, the positivist or 'scientific' approach has informed the prevailing view of health care. The concept of positivism was introduced by Auguste Comte whose view of science was one in which 'facts are linked in terms of ideas or general laws of an entirely positive order suggested or confirmed by the facts themselves' (Acton 1951:292). The positivist approach assumes an objective reality which is observable and measurable, where numerical data is obtained, whereas the lived experience is more naturalistic and holistic (Polit & Beck 2008).

Post-Positivism and Post-Modernism

Post positivism is an alternative epistemological position to positivism, a critical paradigm which challenges the objective detachment of the positivist (Guba & Lincoln 1994). Post positivists and post modernists expound views that reality is more than the observable (Rolfe 2006). Human experience is greater than the objective and deductive findings of hypothesis testing and is not solely a biomedical process to be observed and measured (Bury 1982). In emphasising the importance and uniqueness

of individual experience, post-positivism is inclusive of social and psychological expression. Post positivism is hailed as an ethical way of approaching the social world which is greater than the objectively measurable world and embraces the world of human experience (Foucault 2012).

The main endorsement for post-positivism, and critique of positivism and measurement, is that human experience is not easily reduced to discrete subjective and objective components (Denzin & Lincoln 1994). Indeed, different people may have the same experience but for each person it holds a different meaning (Giddens 1991). Berwick contends that positivism either ignores or misrepresents the personal experience of individual health care users (Berwick 2008). However, Foucault argues that modern medicine is informed by the experience of situations rather than objective measurement (Foucault 2012). Moreover, Carla Willig (2001:9) suggests that the qualitative researcher aims to understand 'what it is like' to experience particular things such as illness.

Interpretivism

Interpretivism is a post-modern research philosophy purpose of which is to acquire meaning and understanding (Creswell 2012). One ontological assumption of interpretivism is that understanding of the world is that experiences are not only observed they are interpreted (Crotty 2003). Whereas positivists believe that reality is separate from the individual who observes it, interpretivists argue that reality and the individual who observes it cannot be separated (Guba & Lincoln 1994, Creswell 2012). The interpretivist stance is that social reality is effectively subjective, people seek to understand knowledge based on social reality and make their own meaning of events through direct experience of themselves or others.

If one acknowledges that knowledge, of which experience is a part of the whole, is co-produced between experiencing person and others then this might lead towards a social constructionist view of experience (Bury 1982). This is not to say that knowledge is always a co-production but must be known to both the experiencing person through whose experience the knowledge may be mediated and thus subject

to interpretation. In the context of pain, the experiencing person may know and express that they have pain which is mediated by experience and context, including the nature of the relationship with the observer to whom it is expressed. Indeed, pain is an abstract concept, difficult to define and challenging to measure. Moreover, pain, just as beauty, is in the (metaphorical) eye of the beholder.

If the world and knowledge of pain is open to interpretation through our perceptions of reality then all knowledge of pain is individual and subjective. Hence, the individual experience of cancer pain cannot be examined or described in terms which are quantitative. Human experience is not objective but effectively embodied in the behaviours, emotions and thoughts of an individual, the antithesis of positivism (Merleau-Ponty 1945/2009, Giddens 1991, Crotty 2003). The contemporary perspective is that neither the 'scientific' nor the qualitative approach can claim to give the whole picture. Both provide different types of knowledge about phenomena and either may be suited to the study dependent on the problem or research question (Devers 1999, Klassen *et al* 2012). Hence, a post-positivist perspective may best fit the premise for this study because it seeks to capture experience through the rich descriptions of participants.

3.2.3 Philosophy of Pain and Illness -*The Argument for a Qualitative Approach*

Pain is not a linear or a singular variable and may originate in the somatosensory system, cognitive perceptions or emotions (Treede *et al* 2008). Whilst, the dominant view of health and disease is primarily informed by the objectivist and positivist stance, the reality of pain is that it is experienced as a subjective state by a human being and informed by many factors (Hadjistavropoulos *et al* 2007). These factors include biopsychosocial variables which may inform recurrence, severity and expression of pain as well as being influential in the way pain affects the lives of individuals. Understanding these factors may yield insight into development of understanding of the lived experience of having cancer and pain in later life.

Pain is an inherently subjective experience, where one is reliant upon the primary report of the person experiencing pain. Seeing that someone is apparently suffering and distressed by the severity of their symptoms is not sufficient to identify pain. Diagnosis of pain and agreement about the severity of cancer pain is particularly challenging (Haugen *et al* 2010, Bennett *et al* 2012, Burton *et al* 2014). Though pain is appreciated in our common human understanding, there is an argument about whether pain is a sensory experience, stimulus response or an affective (emotional) response to a physical or emotional stimulus (Perl 2007, Breivik *et al* 2008). This is reflected in the definition of pain adopted by the International Association for the Study of Pain (IASP):

An unpleasant sensory and emotional experience in association with actual or potential tissue damage, or described in terms of such damage

(Merskey 1994:210)

In practice, cancer pain especially may not be described in language that relates to tissue damage or expressed in any terms at all (Bennett *et al* 2012). Thus, from the perspective or view of a third party, pain may not be visible or quantifiable.

The concepts of illness and disease are also problematic insofar as they may reflect the differences between the subjective experience of illness and that of the diagnosable, observable and measurable disease (Surbone *et al* 2007, Godfrey & Townsend 2008). The distinct concepts of illness and disease are akin to the separation between the physiology of pain (somatic experience) and the subjective psychology of pain (psychogenic experience) (Fernandez & Turk 1995). But, it is the complex nature of human experience, not its subjectivity, which is problematic and difficult to understand. Disease implies diagnosis and labelling by health professionals, and the words disease and illness may reflect different perspectives on the same phenomenon (Bury 1991, Kelly & Dickinson 1997). To address these varied perspectives, and the perceived 'health illness divide', the biopsychosocial model was developed to enhance

appreciation of the biological, psychological and social experience of disease (Yardley 1997).

The philosophical position of the pain experience has been further informed by recognition of the complex physical, affective sociocultural dimensions of the pain experience (McGuire 1995, Turk *et al* 2009). The physical, psychological, social, emotional and spiritual pain experience of those with advanced and terminal cancer was conceptualised as 'total pain' by Dame Cicely Saunders after her substantial research based on hospice patient's narrative accounts of their cancer and pain experiences (Clark 1999). This 'total pain' experience may be expressed in narrative form verbal or written by the experiencing person. Therefore, symptoms are narrative expressions of the whole experience and the inseparability of bodily experience from the whole is the personal conceptualisation of the lived experience of pain.

There is an additional potential conflict in philosophy and paradigmatic stance which arises from the use of the word 'experience' and its meaning in a health care context. Experience could be viewed from a positivist stance or a variety of other, not mutually exclusive, qualitative perspectives including grounded theory and phenomenology (Creswell 2012). The scientific or positivist approach to reality is sometimes informed by the Cartesian dualism of mind and body (Paulson & Willig 2008). Descartes' theory of dualism was an attempt to separate the person from their empirical self and to describe the thinking talking individual as distinct from their observable physical form. The antithesis of this perspective has been described as the embodied self where reality is the combined wholeness and inseparable reality of self and body (Merleau-Ponty 1945/2009, Wilde 1999, Williams 2006). An individual is necessarily and undeniably a physical presence combined with a conscious, sentient, emotional sensibility which allows for experiences of pain and pleasure.

The insider's perspective is generated from the unique descriptions of the individual to gain a unique perspective on the lived experience. The researcher's personal views, observations and reflections may contribute an outsider's perspective to the experience, which may be biased towards the researcher's world view. These views,

combined with an understanding of some of the physical considerations of the experience of consideration of the cancer pain experience, may be viewed as supporting an holistic perspective on the whole experience of pain. The subjective reality of pain, which is real to the experiencing person, may be at any point co-constructed between experiencing person and observer and may not be the only reality of that experience. Therefore, once interaction is introduced into the appreciation of knowledge then constructionists would argue that knowledge is co-produced with layers of complexity compounded through previous experiences, knowledge and use of language (Guba & Lincoln 1994, Creswell 2012). These philosophical assumptions, researcher's beliefs and world-view are integral to appreciation of how the research engages with the experience of having cancer and pain.

3.2.4 Phenomenology as Philosophy

Phenomenology is a philosophical framework which considers experiences and how these are structured in consciousness (Merleau-Ponty 1945/2009, Ashworth & Cheung 1997). The individual experience of pain may be positioned in the philosophical and phenomenological position of embodiment (Merleau-Ponty 1945/2009). Embodiment is a concept which challenges the divide between mind and body and is the phenomenological theoretical position of describing the individual as both 'having a body' and 'being'¹³, thereby emphasising the physical and existential aspects of existence and perception. Merleau-Ponty (1945/2009: 94) further considers the experience of pain in the *body as lived* and experienced as part of the world to which it belongs.

This concept of the life as lived (embodied) and experienced is one which incorporates the thoughts and meanings as known to the person experiencing the phenomenon and is not necessarily the same as the life as told (narrative). Thus, the narrative is always

¹³ Merleau-Ponty considers that it is not possible to describe an experience without considering the perspective from which the observation must arise. A boundary exists between the first person and third person perspective; that of the observed (having a body) and the embodied or lived experience (being)

that part of the experience that the experiencing person is willing and able to share. Furthermore, narrative may contribute to a phenomenological understanding of the lived experience but can never be a full exposition of life as lived and experienced (Clanidin 2006, Ollerenshaw & Creswell 2002).

If pain is difficult to understand or identify then phenomenology may offer a way to appreciate the experience of pain and its effects. Merleau-Ponty's transcendental philosophy offers an approach to the phenomenology of meaning. Merleau-Ponty argues that experience is presented in language and yet language is a barrier to meaning itself. In particular relation to perception, Merleau-Ponty deals with the body and sensation in great detail in his *Phenomenology of Perception* (1945/2009).

The body is the vehicle of being in the world, and having a body is, for a living creature, to be involved in a definite environment, to identify oneself with various projects and be continually committed to them (Merleau-Ponty 1945/2009:94).

Phenomenology is a philosophical movement which considers experience as experienced by an individual or individuals. Husserl introduced phenomenology as a form of 'descriptive psychology' or study of perception (Husserl 1913/1962). Husserl advanced the concept of transcendental phenomenology, through which he wished to establish a foundation for science and philosophy.

Husserl first projected the idea of the 'lived-body' to separate the concepts of the physical body from the body that is lived in and perceived. In this separation he considered the notion of intentionality as being bound with the world as experienced (Dowling 2007). That is, experiences are directed at things in the world. For Husserl, consciousness has to be intentionally¹⁴ experienced in order to exist. In Husserl's philosophy it is not the notion of the object, or phenomena of interest, which is

¹⁴ Intentionally and intentionality or directedness in this context are used to consider thinking *about* something or directing ones thoughts towards an object or experience which may be real or perceived (subjective).

important but the experience of the object of which one must take note. Husserl referred to this as the *noema* of experience (Zahavi 2004).

Merleau-Ponty followed Husserl in the development of existential phenomenology (Merleau-Ponty 1945/2009). However, he attacked the Cartesian concept of embodiment and relocated the notion of intentionality within the body-as-lived. Whereas Husserl focused on perception and observation, including abstract phenomena, Merleau-Ponty's existential phenomenology focused on bodily perceptions and existence in space and time. He considered the body itself, as the fundamental locus of all life and all knowledge, as the foundation for his philosophy on phenomenology.

“Insofar as, when I reflect on the essence of subjectivity, I find it bound up with that of the body and that of the world, this is because my existence as subjectivity (inter alia consciousness) is merely one with my existence as a body and with the existence of the world, and because the subject that I am, when taken concretely, is inseparable from this body and this world”

(Merleau-Ponty 1945/2009: 475)

Merleau-Ponty considered that phenomenological analysis has to begin with an appreciation of the lived-body as it exists in time and place, in other words in its environmental and spatiotemporal context. Thus, he challenged the objectivist position and reductionist world view of experience. Merleau-Ponty argued that objectivist science cannot describe the true nature of perception and phenomenology affirms perceptual experience and meaning as lived by bodies (people) (Zahavi 2007). In this he proposed a philosophy where perceptions and sensations are subjective, but no less valuable than objective ones, and meaning clings to certain contexts.

Merleau-Ponty viewed experience as a subjective synthesis of multiple sensations and perceptions (Merleau-Ponty 1945/2009). He further argued that the expression of experience is through language but that not all experiences are expressed and thus there is a reliance on language for the expression of experience. Furthermore, the

expression of language assumes a shared knowledge of the world and its language. Pain, as an experience, is also personal and subjective. The experience of pain is abstract and cannot be shared with others; it can only be compared and contrasted with experiences of self (for the experiencing person) or aligned with some historical experience of the observer. All of which is mediated in the form of language.

For Merleau-Ponty, pain also has a temporal existence (Merleau-Ponty 1945/2009). Indeed, the temporal nature of chronic pain has been noted as an identifying element in its diagnosis (Gourlay *et al* 2005). Acute pain is transient but chronic pain is not time limited. However, cancer pain is a combination of acute and chronic pain. In this regard, cancer pain is both complex and anomalous in its management and individual in its presentation (Burton *et al* 2007). Thus, in his subjective and experience based view of perception, Merleau-Ponty's philosophy lends itself suitable for the consideration of things such as pain which are not observable objects but nonetheless have an enormous effect on the experiencing person (Bendelow & Williams 2014).

3.3 Qualitative Research Methodology

For this study, the choice of paradigm or way of viewing the world, as a researcher and health professional, should be patient-centred and one of qualitative enquiry because the question, *to understand the experience*, cannot be answered solely with 'scientific methods' (Denzin & Lincoln 1998). Furthermore, objective pain measures and 'tools' are creations of natural science, limited in their appropriate and effective use because of attempts to quantify a subjective experience (Herr & Garrand 2001). Also, Dilthey maintained that the natural sciences do not offer meaningful, interpretive constructions of the cultural environment and lived experience (Dilthey 1976). Dilthey further suggested that experiences are mental and social constructions which are contextually sensitive. The contextual experience of illness and willingness to appreciate the complexity of how this experience contributes to the whole is expressed in the tenets and ideals of patient centred and holistic care.

Phenomenology concerns itself with experience and embodied meanings. A phenomenological approach is appropriate for the exploration of a subjective experience, such as pain, in the context of living with cancer (Seymour & Clark 1998). Objective pain measures and 'tools' can be considered as creations of natural science which are limited in their ability to capture the whole experience of living with cancer and pain (Herr & Garrand 2001). To understand the experience of cancer pain will draw upon the importance of the personal perspective of the experiencing person rather than the view of the researcher (Polit & Beck 2008). Thus, understanding the experience of cancer pain may be considered as more than the measurement of pain and may be expressed in the concepts of patient centred and holistic care (McCormack 2003, Nolan *et al* 2004, Ellis 2009, McCance *et al* 2011). Qualitative approaches, such as phenomenology, may offer a meaningful opportunity to consider the construction of the lived experience (Dilthey 1976).

3.3.1 Interpretative Phenomenological Analysis

A qualitative methodological framework will ensure that this subjective and potentially sensitive experience is considered with empathy and compassion whilst ensuring a rigorous approach to the data (Baert 2003). Interpretive phenomenological analysis (IPA) is a pragmatic research methodology developed initially for health psychology which is appropriate to consider the unique personal experience of living with disease (Smith *et al* 1999). IPA is based on the philosophical works of Husserl and Heidegger (Smith 2004). It is also useful for the consideration of data when it is important to respect an individual's account of their experience (Smith 1996). IPA has three elements: phenomenology, hermeneutics and idiography.

Phenomenology

The first of these elements, phenomenology, as considered by Smith (2004), is an adaptation of a theoretical position toward viewing the world and is strongly associated with the interpretative and hermeneutic rather than the descriptive. However, it is an approach to conducting research rather than a true philosophy and also has its origins in symbolic interactionism (Brocki & Wearden 2006).

When considering the application of phenomenology, Heidegger developed the concept of Dasein or 'being in the world' to suggest that we are part of the world around us (Sheehan 2008). Through this, people's connection or engagement with the world and the objects in it cannot be easily separated from the experience.

Intentionality, in this context, is the whole and inseparable experience of the world as an intentional act.

Merleau-Ponty further described a pre-reflective intentionality in developing his theory of embodiment, the 'human body is an object amongst other objects' as well as time (Reuter 1999: 72). Thus, understanding can only be achieved if one acknowledges the context of the whole and for IPA phenomenology is a method rather than a methodological approach.

Hermeneutics

The second of the theoretical foundations of IPA is hermeneutics or interpretation. Hermeneutics has its origins in the interpretation of religious texts in order to gain a deeper understanding of the context and original intentions of the author. Heidegger considered that phenomenology was a hermeneutic process. In contrast Merleau-Ponty has suggested that language and experience co-exist but are not as strongly aligned because of the absolute need for all words to be accurately representative of meaning (Dowling 2007).

One of the principle features of hermeneutic theory is the notion of the hermeneutic circle. This is the circular and repetitive process of going to and fro amongst the data to find meaning through interpretation (Sadala & Adorno 2002). In considering the minutiae of text, the detail and small subtleties, the whole can be better appreciated. This non-linear process is described by Larkin *et al* (2006: 113) in stating:

"Any interpretation necessarily involves an essential circularity of understanding".

Heidegger argued that in accessing the hermeneutic circle the researcher becomes empathetic with the participant and adapts their ideas and assumptions about the

experience to become closer to the participant's world view (Smith *et al* 2009). Thus, the hermeneutic circle becomes part of the reflexive process and becomes a key aspect of the application of IPA.

Idiography

Another foundation of IPA is its respect for the individual or unique facts rather than the general (Smith *et al* 1995). Idiography contrasts markedly with traditional nomothetic health services research which seeks to make reference to wider groups or populations and has a predictive or deterministic component. The process of IPA is described by Smith (2004) as:

“...starting with the detailed examination of one case until some degree of closure or gestalt has been achieved, then moving to a detailed analysis of the second case, and so on through the corpus of cases. Only when that has been achieved, is there an attempt to conduct a cross-case analysis as the tables of themes for each individual are interrogated for convergence and divergence” . (Smith 2004:41)

As such Smith presents the importance of IPA in the examination of the individual. Phenomenology, through the application of IPA, allows emphasis on the rich and personal accounts of individuals. IPA embraces the unique and complex nature of lived experience through its idiosyncratic idiographic approach to representing the individual rather than the group. IPA only describes and supports interpretation of these rich accounts of individual experience (Willig 2001). Hence, this current study attempts to make no claims related to generalisation but may be able to add to other similar small studies on the same topic or generate areas for further enquiry.

Process of IPA

IPA focuses on making sense of the lived experience of a phenomenon, the understanding of what people know or believe they know (Smith *et al* 2009). IPA relies

upon social cognition theory¹⁵ as opposed to discourse analysis¹⁶ and there being a direct connection between experiences, thoughts and verbal expression (Smith 1996). Social cognition theory has its origins in psychology based on the natural sciences with an aim to make predictions and associations which are comparable to quantifying the human experience (Langdrige 2007). Smith proposes that IPA can 'mediate between the opposed positions of social cognition and discourse analysis' (Smith 1996: 264). Within the tenets of IPA, 'the importance of context and language ... means IPA can also engage in a fruitful dialogue with discourse analysis' (Smith 1996: 264). Indeed, IPA may be identified as discursive in the way it interprets reality, bridging the gap between the positions of the positivist and interpretivist paradigms (Shaw 2010).

IPA may be situated within the constructivist epistemology as it may engage directly with individual ideas and theoretical constructs (Larkin *et al* 2006:104). In this IPA may be distinguished from grounded theory as IPA does not set out to establish new theory. Both approaches use systematic step by step approach to data analysis however IPA focuses on the unique phenomenological account of the individual. Also, grounded theory uses the data from one participant to inform the next interview whereas IPA takes an idiographic approach to each person's data.

IPA uses a detailed and rigorous approach to make sense of a research participant's experiences (Smith *et al* 2009). Notably, Merleau-Ponty suggests that phenomenology is more than an examination of subjective experiences, rather an alternative expression of reality to that expressed through cognitive science (Merleau-Ponty 1945/2009). According to Smith, IPA acknowledges context and the limitations of traditional quantitative methods to consider cognition and human experience (Smith 1996). Yet, this is disputed by Willig (2008) who suggests that this emphasis on cognition is not compatible with phenomenology because IPA is about studying people's lived experiences not people's cognition.

¹⁵ Bandura 1977

¹⁶ Potter & Weatherall 1987

Limitations of Interpretative Phenomenological Analysis

IPA has advantages for a study which respects the unique human experience. However, it also has some shortcomings. There are issues with the use and appreciation of communication. IPA relies on data, usually collected from interviews with participants. Language through conversation is the medium by which participants communicate their experiences (Willig 2008, Smith *et al* 2009). Hence, a major assumption of IPA is that experience can be described in language which encompasses said experience and that all parties have the same understanding of the words used. Indeed, the word *pain* can imply a variety of individual senses and experiences, which are informed by current and previous experiences, as suggested by the International Association for the Study of Pain's definition referred to above (Section 3.2.3).

Interpreting expressions from a narrative account of experience may be a personal process and thus a potentially limited way of presenting the reality of the experience as lived. Language and meaning is subject to the intention, the context, body language and the skill of the interviewer. Indeed, uncovering meaning through use of language is part of the phenomenological approach to 'describe the essence of being' (Osborn & Smith 1998).

The interpretative nature of IPA means that, since data is usually collected in the form of interviews from two parties, the interviewer and the interviewee, then language by implication is the means by which participants convey their lived experiences (Smith *et al* 2009). If language involves interaction, then language could be said to construct rather than describe the lived experience of another person. Indeed, discourse analysis may provide an alternative way to explore the effects of social interaction and context on the construction of a phenomenon such as lived experience (Willig 2008). From this perspective the use of language is both an enabling and a limiting factor in the understanding of another person's experience and language can limit the expression of experience (Willig 2008).

Also, one must be cautious not to assume that one interview can give a complete picture of a lived experience. IPA relies on the participant to share their experience

through rich descriptions (Smith et al 2009). In contrast, Willig argues that phenomenology should consider a pure unmediated account of experience as per the Husserlian concept of transcendental phenomenology (Willig 2001). Therefore, many who would either be unable or unwilling to give such a rich description, might be considered unsuitable participants in an IPA study (Willig 2008).

Any methodology will have limitations in its ability to expose the whole private and subjective experience to public scrutiny. Furthermore, the interpretation may represent only a fragment or snapshot of a whole more complex reality. This necessary subjectivity represents a substantial potential barrier to the expression of rigour in any findings. But, it must be noted that pain has no linear and objective measure and pain's validity lies in the trust and belief of the observing person to acknowledge and endorse the reported account of pain, however expressed.

3.4 Summary

This chapter has described the philosophical, ontological, epistemological and methodological underpinnings of this study. Reconciliation between positivist and some qualitative world views is not easily achieved and does not readily support the ideals of holistic 'person centred care'. This has led to the adoption of the qualitative methodological approach taken here.

This study will avoid an overtly positivist or interpretivist approach and will take a pragmatic approach to the methodology and methods used. The methods used are highly influenced by the phenomenological philosophical perspectives of Maurice Merleau-Ponty (1945/2009), informed by the constructivist stance of Creswell (2012). However, the methodology is largely a pragmatic application of IPA which will be further elaborated in the next chapter.

Chapter 4

Study Design & Methods

4.1 Introduction

In the previous chapter the theoretical perspectives which informed the research design were summarised. This chapter describes the research design and provides a rationale for the choice of methods developed in response to the research question. It reports the conduct of the study, the sampling and recruitment procedures, negotiating access to research participants and the approach taken to address ethical concerns. The application of IPA as the method of data analysis is detailed. The final section considers reflections on method and the reflexive stance of the researcher.

4.1.1 Background and research purpose

In chapter 2, a review of the literature concluded that relatively little is known about the experiences of older people with cancer pain. Older people have been neglected in studies of cancer and pain.

The purpose of this research is to consider how the older person constructs the experience of cancer pain and how this is informed by expectations and experiences.

Objectives

- To understand the experience of cancer pain in older people
- To illuminate underlying themes and contexts that may account for this experience.

This section considers how methodological considerations, as described in chapter 3, have influenced and informed the choice of research methods. Understanding a subjective phenomenon, such as older people's cancer pain, might be achieved through consideration of the individual accounts of older people with cancer. Drawing on phenomenological perspectives on the lived experience of others led to

consideration of Interpretative Phenomenological Analysis (IPA) as developed by Jonathon Smith (Smith 1996). The idiographic nature of IPA allows for the exploration of an individual making sense of a given phenomenon. It assumes all participants are actively engaged in the interpretation of their own subjective world, in this case the experience of pain and cancer (Biggerstaff & Thompson 2008).

4.2 Methodological Orientation and Theory

As discussed in chapter 3 quantitative methods may provide data on a variety of specific observable aspects of healthcare and illness management. However, quantitative methods do not provide insight into the subjective experience of healthcare or living with illness from the standpoint of the experiencing person. Qualitative approaches are suitable for capturing individual issues, cases or events in depth and detail (Patton 2002). The individual's experience of living with cancer and pain can be captured through qualitative methods provided that these are rigorous and thorough in their approach to ensure the accuracy of representing the individual experience and an appreciation of the complex nature of illness (Mays & Pope 2000). Interpretive phenomenological analysis (IPA) is widely established in both psychology and health care and has established methodological rigour (Smith 1996, Smith 1999, Willig 2001, Smith, 2004, Biggerstaff & Thompson 2008). Indeed, a phenomenological approach is appropriate for the exploration of a subjective experience, such as pain, in the context of living with cancer, particularly where the meaning of living with pain and cancer are to be considered (Seymour & Clark 1998, Smith 1999). A research programme that aims to consider the meanings of these experiences fits with an interpretive approach such as IPA.

4.3 Research Methods

The methods used to collect data in this study are suited to IPA in their focus on the unique experience of the individual. Considering different approaches, including using questionnaires and case study approach, methods using the participant's voice, particularly through using a diary-interview method were determined to be most

suitable. Indeed, the diary-interview method is congruent with both phenomenology and patient-centred care (Zimmerman & Weider 1977, Milligan et al 2005).

4.3.1 Diaries

Diaries have been used for the collection of data in both quantitative and qualitative research (Patton 2002, Riff *et al* 2014). Using a solicited personal self-completed diary presents a pragmatic solution to ensuring that the voice of the older person is represented in research (Jacelon & Imperio 2005, Alaszowski 2006:113, Ryan 2006). Their usefulness is established where it is important to capture events and their effects over a defined time period, where memory may be an issue and where context and veracity may be significant (Newton *et al* 2010). Using a diary may also afford the opportunity to reveal things, perhaps thoughts and feelings, and sensitive subjects which might not be easily said to an interviewer (Furness & Garrud 2010). In palliative and cancer care the combined use of diary and interview has been noted as an effective methodology (Richardson & Ream 1996, Sheriliker & Steptoe 2000, Wu & McSweeney 2007, Broom & Tovey 2008, Hermansen-Kobulnicky 2009).

Diaries also have been found to be effective for use over long periods of time and may be useful for exploring and supporting health issues amongst older people in particular. Jacelon & Imperio (2005) noted the benefits of collecting data from older people, from unsolicited diaries. In these diaries the participants were able to note the things that were important and personal to them (Jacelon & Imperio 2005). Use of a solicited health diary may offer valuable insights into daily routines and coping strategies of older people. It can also prove invaluable in identifying subtle aspects of daily lives and routines that impact on health and wellbeing (Milligan *et al* 2005). Collecting chronological and contemporaneous data about living and daily routines through diary use may offer a useful record of health status and the effects on life and the lived experience of disease or health related problems of older people (Maunsell *et al* 2000, Milligan *et al* 2005, Hager & Brockopp 2009, Elg *et al* 2011). The usefulness of keeping pain diaries, for older people with chronic pain, is also long established and has been noted as an aid to supporting the use of psychological therapies in the

management of older people's pain (Helme & Gibson 1998, Morone *et al* 2008, Hager & Brockopp 2009).

Diary use, the structure and suggested prompts (as noted later in 4.7.2 Figure 6) were developed collaboratively with the North Trent Cancer Network Consumer Research Panel (NTCRN CRP) and members of the Specialist Palliative Care Team at Hospice 1.

4.3.2 Interviews

Qualitative interviewing, the second method of data collection to be used in this study, is also widely established as a method of exploring the perspectives of service users in cancer and palliative care (Seymour & Clark 1998, Kvale & Brinkmann 2008, Collins *et al* 2010). Interviewing participants allows participants to be the expert about their experience and facilitates the telling of their story (Smith & Osborn 2008).

The aim of a qualitative interview in palliative care research is to establish rapport with the interviewee which allows them to feel comfortable enough to reveal their thoughts and feelings (Payne 2007). Interviews, as a data collection method for older people, are also a useful route to creating relationships and establishing person-centred care (Clarke *et al* 2003). Interviews can draw the interviewer into the older person's world; however, there are various methodological, ethical and practical considerations when interviewing older people.

Pleschberger *et al* (2011) noted some of the methodological issues which are particular to interviewing older people in receipt of palliative or end of life care. Access and development of rapport of older people may be challenging and is a particular issue in the context of palliative care. The researcher is reliant on gatekeepers, health professionals who introduce the concept of participation and who may be the first informants about the study, its topic and the implications of consenting to participate. This initial encounter may inform the interview and can raise expectations or concerns about the interview process; this must be acknowledged and addressed prior to the commencement of the formal interview (Pleschberger *et al* 2011). Thus, detailed and careful explanation is not only necessary for consent; but, to ensure the development

of a mutual understanding about the study and for building rapport between the interviewee and interviewer.

In preparing for the interviews, it is important to plan for the potential needs and concerns of the participants. Planning to facilitate a pleasant exchange and enable participants to provide a detailed account of their lived experiences is consistent with the aims of the study (Kvale & Brinkmann 2009, Smith *et al* 2009). Engaging the older person with the topic of pain whilst encouraging them to express their lived experiences may be particularly challenging. Indeed, older people may be more reluctant participants than younger ones (Herzog & Rodgers 1988).

There may be other considerations for interviewing older people such as their unique placement culturally and historically related to their war and immediate post war experiences. These historic sociocultural influences may result in an idiosyncratic context and model of living that differentiates older adults' accounts, and willingness to engage in discussions about themselves, from those of their younger counterparts (Kirkevold & Bergland 2007).

Regardless of age of the interviewee another area of concern, when considering the qualitative interview, includes the nature of the relationship between researcher and interviewee. Interviews may be considered a co-construction between the researcher and interviewee (Powell & Biggs 2000, Holstein & Gubrium 2011). Furthermore, the existence of real or perceived power structures may influence what is said and understood.

The interviewer needs to establish rapport with an interviewee to first engage with the potential participant, second to minimise stress and third to facilitate a sufficiently relaxed interaction to allow the participant to talk freely (Locher *et al* 2003). This may be partially achieved through politeness and introductions, use of first names or surnames as preferred by the participant, allowing the participant to choose the venue and times for the interview. Preliminary meetings at the day hospice served to

establish rapport, ensure that participants were fully informed and to begin a professional relationship with each potential participant.

The participant should also feel that the researcher is credible; this should be established as part of the recruitment process but may be reinforced during the interview through behaviour, body language and engagement in active listening (Sixsmith *et al* 2003). Presenting oneself as a smart professional in appearance but not too formally dressed may enhance the participant's confidence in the interviewer.

Older people with cancer and pain are the focus of this study therefore it is conceivable that they might experience physical discomfort at the time of interview (Rustøen 2009). Empathy and understanding are essential requirements for undertaking qualitative research therefore; the participant's welfare must be prioritised over the need for interview data. Thus, should the participant become distressed, the interview may be suspended or postponed until the participant feels able to continue with the conversation. In practice one participant, Dougie was in pain at the time of interview but insisted that the interview should go ahead until his taxi arrived to take him to an urgent GP appointment.

Doing face-to-face research with older people who have a diagnosis of cancer accessing palliative care may also evoke an emotional response from participants for which the researcher needs to be prepared (Dickson-Swift *et al* 2007). Psychological distress is common in people with a cancer diagnosis (Ryan *et al* 2005). Researchers are not immune to feelings of concern and may also experience distress in response to verbal and non-verbal expression of emotions. The expression of emotions may at times be challenging and the interviewer should be prepared to pause or stop the interview. Thus, active listening, showing empathy and the ability to identify the verbal and non-verbal cues may aid the development of rapport and empathy needed to support people who are distressed (Egan 1994). Participants were informed verbally of the possible risks and benefits of participation and this was reinforced in the written information given when consenting to participate (Appendix H). This extract from the

NHS REC form as submitted for ethics approval demonstrates the stance adopted by the researcher:

A62. Summary of main issues. Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.

The main risk to participants is the possibility of distress or discomfort when discussing a sensitive issue such as cancer pain. Cancer, because of its associations with suffering and reduced life expectancy, can be an emotive and sensitive area for research. These issues will be addressed by using a sensitive approach to questioning. The participants will be reassured that they do not have to answer any question if it upsets them. Additionally, participants will be advised that all communications (diaries and interview responses) will be kept confidential. Apparently innocent and innocuous questions about the participant's life and family may give rise to painful emotions and thoughts and distress for the participant. If this happens the researcher will respond appropriately as an experienced registered nurse and if needed take advice from the palliative care team. Also, the participants will be advised that if they have concerns, expert counselling services are accessible via the palliative care team or the GP. Furthermore, the researcher is a Registered Nurse and has much experience of dealing with sensitive questioning both from her years working as a pain nurse specialist and more recently as a researcher.

History and storytelling are acknowledged aspects of narrative research methods with older people accessing health care (Clarke *et al* 2003, Buckley *et al* 2013). The management of storytelling may be challenging as it could be viewed as a diversion from the purpose of the study. However, storytelling may include life histories which prove invaluable for gaining rapport and access to a greater appreciation of the context of the lived experience of illness (Koch *et al* 2010). Storytelling may also help the researcher to make sense of the rich lives of research participants and the challenges which face them.

Interviews are also a way of trying to interpret the participant experience through listening to an account of that experience (Kvale & Flick 2006). This interpretative method is referred to as the 'double hermeneutic'¹⁷ experience because the researcher is interpreting or making sense of the participant making sense of their experience (Smith & Osborn 2008, Smith *et al* 2009). Phenomenological approaches can be used to access meaning and can be extracted from interview narratives of lived experience (Kvale & Brinkman 2009:29).

4.4 Sampling

4.4.1 Participant Selection

A purposive sampling strategy was used so as to be representative of the phenomena of interest (Richie & Lewis 2003:79). The sample size in qualitative research studies is usually small because of the in-depth nature of data collection methods (Crouch & McKenzie 2006), see for example McWilliam *et al* (2000), Tamura *et al* (2006), Evans & Hallett (2007), Röing *et al* (2007), Doumit *et al* (2008). The theoretical position of IPA similarly suggests a small sample size, because of the detailed analysis which this approach requires and to ensure that the phenomena of the individual experience is adequately illuminated without loss of nuance and subtle meaning (Smith *et al* 1999, Brocki & Weardon 2006, Baker & Edwards 2012).

The developing advice for IPA is that smaller samples are best as large samples may lead to superficial understanding (Smith 2003). The sample sizes which have been used for IPA, typically range from one to fifteen (Bramley & Eatough 2005). IPA samples are usually small also to reflect the particular rather than the general nature of human experience and to provide sufficient perspective and adequate opportunity for scrutiny (Smith & Osborn 2008:56). IPA involves a lengthy and detailed analysis of individual

¹⁷ Hermeneutics is interpretation. Double hermeneutic is a theory first expounded by Anthony Giddens (1987) to explain the two way interaction between the lay person and the social scientist that is the complexity of interpretation of another's experience by a third party. It attempts to address the complexity of searching for meaning in an experience of another. In IPA there are two interpretations the experiencing person making sense of their own experience and the listener inevitably interprets the account of the experiencing person.

transcripts; it is an idiographic method (Smith *et al* 2009:59). Idiography focuses on unique facts and detailed features of individuals within their particular social and cultural context, rather than making broad generalisations about people's behaviour. IPA is concerned with the particular aspect of experience that makes each individual distinct from other people so as to enhance and add meaning to the analysis. IPA also sets out to 'properly explore, understand and communicate the experiences and viewpoints offered by its participants' (Larkin *et al* 2006:103). Hence, small sample sizes are the norm in IPA studies.

The number of participants was also informed by pragmatic reasons of the timescale available for completion of this study and the potential volume of generated data. The sample was therefore limited to approximately ten participants. In the end it took 18 months to recruit and retain nine participants which was adequate for obtaining rich data.

Inclusion Criteria¹⁸:

- Aged 65 years and above
- Diagnosis of cancer
- Awareness of diagnosis
- In receipt of community based specialist palliative care services
- Experience of pain as a symptom of cancer or subsequent treatment
- Living at home, not in institutional care.
- People who have capacity to consent and complete the diary¹⁹

The above criteria were informed by the following considerations for purposive sampling of participants and because of the limited research noted in chapter 2.

First, the age of recruits has been considered as few studies have considered older people's cancer experiences, in particular people aged 75 and older, who are referred to as the oldest old, have had little representation in recently published research data

¹⁸ The above criteria were modified from their original intent to recruit those over 75 because of recruitment concerns and are discussed later in the chapter, a major modification to the original protocol was sought and obtained from the NHS Research Ethics Committee and the NHS Governance Departments (Appendix K).

¹⁹ In the opinion of the specialist palliative care team.

(Thomé *et al* 2003, Chouliara 2004, Davies *et al* 2010, Dunham *et al* 2013). Second, older people are largely excluded from cancer studies; this is of concern as the oldest old are the fastest growing sub group of the UK older population (Breivik *et al* 2009, ONS 2012). Third, older people in receipt of specialist palliative care have not been the subject of recent study (Devane 2009). Fourth, cancer incidence is greatest in those aged over 60 years, notably breast, lung, colorectal and prostate cancers (Yanick & Ries 2004, DH Cancer Reform Strategy 2007). For those aged 75 and older there is an increased risk of experiencing pain following treatment, including surgery, chemotherapy or radiotherapy, or from metastases as reflected in a recent UK cohort study (Jordan *et al* 2013). Finally, as less than 5% of people aged 60 and older live in institutional care it would seem appropriate to consider the experiences and needs of the majority of older people who live in their own homes (CSCI 2006). Using data from older people who are usually resident in their own homes may also provide more natural data in a context where they are more likely to freely express their experiences and concerns. Indeed, home is also the preferred place of care for many older people (CSCI 2006).

Exclusion Criteria

- People who cannot speak or understand English
- People who cannot write or read English
- People who are unable to provide informed consent, or too ill or distressed to take part.

The choice to exclude non-English speakers was made for pragmatic reasons of time and limited resources. In the geographical areas under consideration local population census data suggested that ethnic diversity in this age group was low compared to younger populations. However, the experiences of older people who do not speak English and other minority groups are worthy of separate study (Jiwa 1999). A video or audio diary would have been considered had sufficient resource been available to provide for this. Similarly, translation services will be considered in future study.

4.5 Recruitment Concerns and Ethical Considerations

Prior to commencement of the study ethical approval was obtained from the University, the local NHS Research Ethics Committee (NHS REC 12/YH/0476) and NHS R&D Departments. The approval was obtained in this order: University Faculty Ethics Review obtained August 2012, 21st November NHS REC favourable ethical opinion and December 2012 NHS R&D approval²⁰. As no clinical intervention or drug trial was involved, in this low risk study, advice was sought informally as to whether a Proportionate Review²¹ might be considered. However, as the study involved a potentially vulnerable group accessing palliative care services the study was referred to the full ethics committee for approval.

Two major ethical issues informed the development of this study. The first issue is that of whether it is in the interests of those people who are in receipt of palliative care and possibly near the end of their lives to be subject to intrusive or distressing research. The concept of researching with older people with cancer in receipt of specialist palliative care is contentious. There is a popular movement which endorses that people with cancer, who are near the end of life, should have their privacy and dignity protected²² as noted in the UK Department of Health's 'Dignity in Care Campaign' (DH 2006). Indeed, de Raeve (1994) suggests that research is never justifiable in this group.

'People with palliative care needs are vulnerable and this makes palliative care research a 'special case'...research is not justifiable in this group'

(de Raeve 1994: 298)

However, it can be argued that people with cancer and in receipt of specialist palliative care may be regarded as exceptionally vulnerable but, still need appropriate evidence based quality effective care (Seymour & Skilbeck 2002).

²⁰ See Appendix M for a timeline of ethics, revisions & governance

²¹ Studies involving minimal risk, burden or intrusion can be accepted for the Proportionate Review Service.

²² National End of Life Care Programme www.endoflifecareforadults.nhs.uk
Dignity in Care Campaign www.dhcarenetworks.org.uk/dignityincare
Social Care Institute for Excellence (SCIE) Guide 15: Dignity in Care
<http://www.scie.org.uk/publications/guides/guide15/index.asp>

The second ethical issue for this study was that the vulnerable and frail older person might be similarly in need of protection from exploitation. To be old may be perceived as being vulnerable and research with the vulnerable may be considered inappropriate (Jacobson 2005, Raudonis 1992).

The vulnerable person is defined as:

‘...a person aged 18 or over, who is in receipt of or may be in need of community care services, by reason of mental or other disability, age or illness, and who is or may be unable to take care of him or herself, or unable to protect him or herself against significant harm or exploitation’
(DH 2000)²³

The third party, family member’s, voice and perspective is considered a valid alternative to using the individual voice and has been used widely to inform care and development of research studies (Seale & Kelly 1997, Seamark *et al* 1998, Hanratty 2000, Koffman & Higginson 2001, Armes & Addington-Hall 2003, Bradburn & Maher 2005, Donovan *et al* 2005, Steinhauser *et al* 2006). In particular, the VOICES tool which captures the retrospective account of carers has acknowledged reliability and validity in many countries and languages (Dunkley *et al* 2003). But, this protective desire to shield vulnerable people from participation in research may effectively mean that people with cancer are denied a voice and may therefore be directly denied an opportunity to influence care provision (Seymour & Skilbeck 2002).

Despite the risks, particularly to the vulnerable or old, with cancer and poor prognosis, there may be benefits of researching with this particular group which outweigh any risks. NICE guidance for research on Cancer Service Development (CSGSP NICE 2004) encourages the involvement of people affected by cancer. Indeed, people with cancer and in receipt of specialist palliative care may be regarded as exceptionally vulnerable

²³ DH (2000) No Secrets: guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse. TSO

but, still need appropriate evidence based quality effective care (Seymour & Skilbeck 2002).

Vulnerability, whether because of diagnosis with a terminal cancer or frail old age, should be acknowledged, in the planning and methodology of a study, to ensure no harm is done (Addington-Hall 2002). However, exclusion on the grounds of age is morally and ethically unjustifiable given that their lack of inclusion does cause difficulties for the management of their care. Indeed, being old does not automatically make one vulnerable but the combination of ageing and cancer might make it more likely. Thus, research with older people with cancer should therefore be subject to special scrutiny.

To ensure the ethical requirements were met, the approval process, methods of recruitment, approach and data collection for this study were designed carefully and sensitively so as to acknowledge any vulnerability and minimise contribution to any distress. The precepts of good ethical practice in human research were adhered to in application of the principles identified in the World Medical Association Declaration of Helsinki (WMA 2008). Autonomy was respected and capacity to consent assumed. Voluntary participation was supported by information supplied in the participant information sheets and elaborated by the researcher. Beneficence was found in the way participants felt valued through participation in the study. The principle of non-maleficence was applied in ensuring that no distress was caused or that it could and would be dealt with if it were. Cancer, because of its associations with suffering and reduced life expectancy, can be an emotive and sensitive area for research (Wilkie 1997, Addington Hall 2007, Allmark *et al* 2009). The privacy and dignity, for each of the participants, was respected in choice of time, venue and duration of interview. Additionally, all recordings and transcripts were anonymised to ensure confidentiality of shared information.

4.6. Recruitment Process

This section details the process of recruiting participants to this study and gives a supporting critique and evaluation of the steps taken.

4.6.1 Setting

The research location consisted of three towns in a post industrial area in the north of England with a total population of 788,300²⁴ with 17% aged 65 or older (Figure 3) and population projections of the oldest old predicted to double by 2028. Initial approach was only made to locality and hospice 1 and later included areas 2 & 3, because of recruitment issues, which are described later in this chapter.

Older population in three Urban Conurbations in the North of England Expressed in number and percentage of the total local populations (Census Data 2011)				
Age	Area 1	Area 2	Area 3	
65-74	24,783 9.6%	22,080 9.5%	27,109 9.0%	
75-84	14,560 5.7%	13,250 5.7%	17,660 5.8%	
85-89	3,684 1.4%	3,279 1.4%	4,346 1.4%	
90+	1,815 0.7%	1,401 0.6%	2,026 0.7%	
Total >65	44,842 17.4%	40,001 17.2%	51,141 16.9%	

Figure 3

The local population also had a higher than regional and national all age cancer mortality. All three towns included in each a district general hospital with cancer treatment, oncology and palliative care services, an hospice and day hospice facility and a community based multidisciplinary palliative care team (MDT). The day hospices were identified as the participant identification centres for patients who were under the care of the local NHS and or the hospice.

²⁴ 2011 Local demographic data from the 2011 Census, Rotherham 254,600, Doncaster 302,400 and Barnsley 231,300

4.6.2 Method of approach

Negotiating access to the clinical areas and research participants was an ongoing activity over a period of 18 months. Meetings with members of the specialist palliative care MDT and members of the nursing teams in the hospices were arranged. At various regular meetings the study was presented and the recruitment process was discussed. Having professional experience and background in nursing was a supportive factor in gaining access to these meetings. However, having the support of various local senior clinicians, including a Consultant in Palliative Care, Consultant Nurse, Nurse Managers and a Senior Matron, were key factors to accessing the various professional communities. Initial scoping with one of the MDT forums provided invaluable insight into the means of accessing the potential participants. At the various meetings concerns and practicalities, related to the recruitment process and the study procedures, were discussed and thus within the scope of the Ethics approval the recruitment process was refined. The health care professionals were provided with information packs²⁵ and agreed to identify people in their care who met the inclusion criteria and give participant invitation letters²⁶ and information leaflets to them.

Potential participants were approached initially by members of the various specialist palliative care and hospice teams to assure no unfair inducement or coercion by the researcher. These staff acted as 'gatekeepers' to potential participants. The NHS ethics approval explicitly stated that contact should be initiated by a third party other than the researcher to ensure no inducement of feelings of obligation towards the researcher (Simm 1991, Rennie 2011). However, the NHS ethics committee permitted and encouraged the researcher's attendance at the day hospices. The researcher was advised to assist with organised activities, in the company of potential participants, to allow informal opportunities to explain the study to those who had been approached by one of the health professionals for inclusion. This proved a very useful and

²⁵ Information packs included invitation letters, information sheets, study reply form, consent form and an addressed freepost envelope (Appendix H)

²⁶ The participant information leaflet and information packs (Appendix H) were developed with the help of older people and service users via the consumer panel of NTCRN before seeking NHS research ethics approval. (PPI -patient and public involvement in research group).

convenient way of maximising time with potential recruits and engaging with the hospice environment.

Potential participants identified by members of the MDT were asked to return the study reply form in a provided stamped addressed envelope. On receipt of the study reply form some of the participants were contacted by telephone to explain any points of query and ask if they would agree to take part. However, for most of the participants, who attended the day hospice, it was convenient to have the same conversation about the study whilst they attended there. These conversations were also an opportunity to ensure the suitability of each participant using the inclusion and exclusion criteria and to build rapport. At a suitable interval, approximately one week following the verbal agreement to participation, potential participants were asked to formally agree and sign a consent form. At this point they were given a two week 'page a day' diary. The invitation to complete the diary was intended to form the first part of the study. A telephone prompt at one week was intended as a supportive measure in the completion of the diary.

The second stage of the study involved an interview with each participant. It was intended that the content of the diary would inform the questions asked at interview with each participant. Using a diary thus might allow each participant the opportunity to elaborate on any points raised and discuss others in greater depth. In the absence of sufficient diary data to encourage the discussion, a semi-structured interview question prompt was kept in reserve. The interviews took place in the research participants' preferred locations and at a mutually convenient time, approximately 4 weeks after the initial appointment. The participants were advised that they could receive a summary of the anonymised analysed findings after all interviews and data analysis was completed but all declined this offer.

Pilot

The first potential participant, identified from the day hospice attendees, had experienced no pain, but offered to trial the diary, gave feedback on the process and positive reinforcement about the outlined diary interview method. Additionally, the

North Trent Cancer Network Consumer Research Panel (NTRN CRP) gave useful advice about administering the diaries and interviewing participants (Collins & Ahmedzai 2005, Collins & Stevens 2006, Collins *et al* 2014).

Figure 4. Recruitment timeline²⁷

	January 2013	November 2013	May 2014	August 2014
Hospice 1	Pilot & recruitment			End of Recruitment
Hospice 2		Recruitment		“
Hospice 3			Recruitment	“

4.6.3 Challenges to participation

In practice, recruitment was challenging and various amendments were made to the initial ethics approval to increase recruits²⁸. Initial attempts to recruit participants aged 75 or older as per the original protocol produced only three recruits in the first six months. The first recruit Ethel completed her diary and interview but the next two participants died before they could complete the study. Following advice from the local palliative care team and lead Consultant in Palliative Medicine the protocol was revised, from the original submission²⁹, to include all cancers and those aged 65 or older. Despite these revisions and many hours attending the day hospice no more participants were forthcoming.

The health professionals and some of the day hospice attendees suggested that the word *pain* might be off putting. Discussion with the NTRN CRP about the information leaflet and the consent form led to another amendment to the research protocol. Thus, a minor amendment to remove the word ‘pain’ from the information and replace with discomfort was agreed. The initial approval had applied to a geographical area

²⁷ & ²⁸

A detailed timeline of all ethics approvals and supporting documentation is included in the Appendix M

²⁹ Amendment to protocol and the original inclusion criteria can be found in Appendix K

rather than one hospice and locality so two more areas were approached at this point and local Governance approval sought. Additionally, the diary was not completed by all participants; advice was sought from the NHS Ethics committee, who after some discussion with them and the local palliative care team, confirmed that the diary should not be a compulsory component of the study but, that it should still be referred to as a 'pain diary'.

Contrasting Hospices and Access Issues

The three hospices and their associated services were all providers of palliative and end of life support, as defined by the World Health Organisation (1990):

'...the active, total care of patients whose disease is not responsive to curative treatment'.

However, their funding, governance and service provision varied considerably. Most hospices in the UK are charitable organisations, with much of their care supported by voluntary services, almost wholly reliant on donations and legacies (Calanzani *et al* 2013). They have been established through local initiatives and largely operate outside the governance and remit of the NHS. In these regards the three hospices were quite dissimilar. Hospice 1 was a charitable organisation with mixed NHS and non NHS Services and mixed charitable and NHS funding, hospice 2 was wholly charity funded but, provided care to people referred from NHS services and hospice 3, unusually, was completely NHS funded. In effect the ethical approvals needed for access varied and are noted in Figure 5.

Figure 5. Ethics and governance variations between hospices

	Funding	NHS REC	Governance
Hospice 1	Charitable & NHS	Only considers 'NHS' patients. Approval as PIC site not NHS provider as some clients not NHS	Local R&D, some clients considered NHS some not so considered by Hospice Governance Committee
Hospice 2	Charitable	Covered by NHS REC approval but not 'NHS' patients	Local R&D approached but advised no governance role. Hence the Hospice's Governance
Hospice 3	NHS	Full NHS REC needed for all access	Local R&D needed for all access

4.6.4 Sample Size

With the advice and support of the NHS REC, who may have anticipated the recruitment challenges, the maximum number of recruits was set at 20 with the intention of seeking approximately 10 participants for the study (as justified in section 4.4.1). In practice, acquiring ten participants was difficult. Approximately eight visits to Hospice 1 were made between January and March 2013. During this time ten potential participants were approached and three agreed to participate, two of whom died before diary completion and interview could be completed. After protocol revisions (as noted in Appendix K) a further four participants were obtained from Hospice 1. Later recruits, one from Hospice 2 and three from hospice 3, increased the total numbers of recruits by four. Thus, a total of eleven people started the study but only nine completed the study and their details are described in chapter 5 (Table 4). In total more than 50 application packs were distributed to potential recruits via the three hospice sites.

4.6.5 Non-Participation

Initial contact via the health care teams produced modest numbers of potential recruits as noted at hospice 1. Unfortunately, no system was established within the

protocol to keep tally of the numbers of all potential participants and their reasons for non inclusion. Thus, the account here is limited and represents only what is known and retrospectively ascertained from personal notes and communications with the various health professionals.

Gatekeeping.

The staff involved in recruitment applied the inclusion and exclusion criteria but admitted to using their own judgement about suitability for participation. It is possible that older people with complex problems may not have been viewed by the health professionals as suitable for inclusion in this study. However, given that many older people with cancer do have complex co morbidities this is unlikely.

The NHS Ethics Committee's strong advisory note to attend the day hospice centres was intended to support the recruitment process; however, it afforded another opportunity for gatekeeping by volunteer and informal caregivers. Indeed, the volunteers were very protective of the day hospice attendees, and though kind, they were frequently intent upon supportive and distractive activities which evaded discussions of pain and other symptoms. This viewpoint that day hospice should be a distraction, and diversion from the burden of living with cancer and the associated distressing daily experiences, was also reiterated by some of the health care professional. The opinion that hospice is a place of safety and security as well as a provider of symptom relief, is widely shared (de Raeve 1994). The Sue Ryder Foundation (2011) commissioned a study to survey and interview experts in the field of palliative care, members of the public and some bereaved relatives about their expectations of hospice based palliative care services which confirmed that safety and security were considerable concerns.

Personal Reasons

Many older people were approached as potential participants but declined when approached because they denied they had pain. Approximately 50 potential participants were approached by the various members of the specialist palliative care teams, however, the majority of the health professionals did not keep any record of

the numbers of people they approached or the numbers of those who refused to participate. One early potential recruit decided that his caring responsibilities for his wife, who had dementia, took precedence. A number of attendees at the three day hospices were also the primary carers for spouses and other close family members. This is reflected in large population data (Vickerstaff *et al* 2009, Carmichael & Ercolani 2014). It is also important to consider that some of the health professionals may have felt unable to assist in seeking potential participants and their wishes were respected.

4.7 Data Collection

Data collection included diary, interview, field notes from the interview setting, personal reflections, kept by the researcher in a reflective journal, and notes from meetings and interactions with members of the MDT who supported this study.

4.7.1 Description of Sample

Participant Profile

The study population consisted of nine men and women aged 67- 88 years, resident in South Yorkshire, diagnosed with cancer, no longer in receipt of curative treatment and having experienced some cancer or cancer treatment related pain. Details about the participants are included in chapter 5 (5.2.1 Table 4).

4.7.2 Administering the Diary

In a preliminary meeting or telephone conversation the researcher introduced herself as a nurse and researcher with a particular interest in the needs and concerns of older people with cancer. Following this initial contact a meeting was arranged to give a formal explanation of the study and to obtain written consent. The diary was offered at this meeting as face to face requests for information in qualitative studies usually achieve a higher response rate (Kelley *et al* 2003, Mealing *et al* 2010). Advice on completion was offered verbally and an information page on completion was included (figure 6). Participants were advised that diary keeping over a period of time can involve a lot of effort and motivation and that it would be better to write a little each

day about anything to help give a picture of their daily lives. The participants were also told that it was also all right to write nothing at all if they felt fatigued or unable to write at any time and that they should not worry about their handwriting, spelling or grammar. Each participant who agreed to complete the diary was contacted by telephone after a week as a supportive midway prompt.

All participants were given the two week 'page-a-day' diary to complete and the diary was well received if not always completed. There were three completed diaries, one partially completed diary because the participant became too ill to finish it and the others had progressive health problems which hindered the completion of the diary. It should be noted that all had either kept their own diary at some recent point in their illness or when asked stated that they would be willing to keep one if it aided their interaction and communication with the health care professionals managing their care.

Figure 6. Information from the 'page a day' diary

<p>Guidance for Keeping this Diary</p> <p>What happened to make you aware of the pain?</p> <p>Where were you?</p> <p>Who else was there?</p> <p>How did it make you feel?</p> <p>How did it limit your activities?</p> <p>Did you do anything to deal with the pain?</p> <p>What did you do and was it effective?</p> <p>Despite the pain, did you manage to enjoy something today, such as a hobby or leisure activity, social visit, going out?</p> <p>These questions are only intended as a guide. If there is anything else about this experience which you want to record please write it here.</p> <p>Please do not worry about handwriting, spelling or grammar. Capturing what you are experiencing and feeling is more important.</p> <p>The researcher will call to collect the diary at a mutually convenient time</p>

4.7.3 Conducting the Interviews

The older people were interviewed in a variety of locations. Privacy and quiet was intended but not always possible because of their preferred choice of location. From the researcher's perspective the hospice was the most convenient location for interview but those interviews which took place in the participants' homes were the most relaxed and informative. Interviews either took place in a private room in the hospice (n=4) to ensure a quiet calm environment or in the participant's own home (n=5) as detailed later in section 5.2.1. The average time of interview was 46 minutes, the shortest was 32 minutes and the longest 69 minutes duration (Table 3)

The interviews were intended to be open and non-directive except for the discussion of the diary content. In anticipation that all participants might not complete the diary, or be as forthcoming in their information as the researcher had expected, a short interview schedule was developed (Figure 7).

Start recording interview.

Reaffirm patient consent and volunteering for interview.

Main Question:

Tell me about your experiences of having cancer and pain ?

Possible prompts:

- What did you feel like....?
- What do you mean by....?
- Tell me more...?
- Can you explain...?

Offer the opportunity for the participant to ask any questions. Offer the opportunity for the participant to share any additional information by telephone or other means if they want to.

Thank the participant for their contribution and time.

Figure 7. Interview schedule

Table 3

Duration of interviews: Mean interview length 46 minutes.

Participant	01	04	05	06	07	08	09	10	11
Duration of interview (mins)	Ethel 47 (32 +15)	Robert 54	John 32	Eric 39	Fred 69	Dougie 45	Ernest 46	Bob 37	Hilda 43
Notes	Interrupted by warden	Background noise of food preparation at the Hospice	The interview was cut short because John wanted to watch the rugby on TV	Eric's wife was present at the start of the interview and brought in teas during	Would have liked the interview to last longer	Was in pain at time of visit and insisted the interview go ahead. Had a doctor's appointment and a taxi booked but he wanted to talk whilst waiting	Interviewed before lunch time so his hunger curtailed the discussion	Fidgety throughout. Smoker.	Interviewed just before lunch with noise and distraction of food preparation outside.

4.7.4 Field Notes

The researcher made notes and recordings of thoughts and feelings about the interviews and interview process before and after each interview. These personal reflections were used to give contemporaneous data in the analysis phase. The notes also included observations about visual appearance, place and other contextual factors which informed the interview conversation. It was noteworthy that some of the participants said much more about having pain and their lives when they were not being recorded.

4.8 Data Organisation

Considerable data in the form of digital recordings, diaries, transcripts and field notes were accumulated. Transcription was initially undertaken by the researcher and later by a professional transcription service. These professionally transcribed interviews were carefully rechecked against the original recording for accuracy by the researcher. Organisation of these data into folders to contain each person's data as a case was used to assist in the referencing and cross referencing process. Individuals were given pseudonyms and each case file numbered to reflect the chronological order of recruitment. As per Sheffield Hallam's University Data Protection Policy and UK data protection legislation, all identifiable electronic personal data was stored securely in the University's server (Data Protection Act 1998). Consent forms and other paper records were kept in a locked desk in a locked office in the University building. Other temporary electronic files, notes and records were stored on a password protected and encrypted data stick.

4.8.1 Data Analysis

The data analysis followed the stages of Interpretive Phenomenological Analysis (IPA) (Smith & Osborn 2008, Smith *et al* 2009: 83). The diary and interview, with each participant, were considered and analysed individually guided by the methods detailed by Willig (2008: 57). Each interview was transcribed and initially coded into sub themes and clustered, ensuring that the connections drew upon the original words and phrases used by the participant. This followed an iterative and logical process, as

detailed below, ensuring that all subthemes were supported with reference to the individual phrase or sentence used. Further, reading and rereading of the transcripts was used to inform connections and clustering of the subordinate themes into emergent themes and finally superordinate concepts. These findings were presented as themes, accompanied by subordinate themes and contextual references from the individual's transcript to represent each as an individual case study. The analysis of each participant's data was a lengthy process, and took approximately one week per case.

Stages of Analysis:

1. Data Immersion: Each diary and transcript was read and re read a number of times. Reading was combined with simultaneously listening to the digital recordings, adding punctuation and ensuring accuracy of the written representation of the data. It was intended that the diary would be used to inform the interview and thus the diary was to be analysed separately from the interview data. In practice this did not happen. Not all participants who initially consented, and agreed, to diary completion were able to do this.

Each diary or transcript of interview was treated as an independent source of data. Each participant's data was considered separately and discretely before considering the next person's data. This was attempted so that the individual perspective was respected and safeguarded from contamination by other's accounts. The reality was that it was not possible to forget the previous participant and ensure that presuppositions were eliminated or that the data from the participants did not become merged.

2. Initial Coding: The content of each diary and transcript were considered, drawing upon the original words and phrases used by the participant, and points of interest or sub themes were identified. Each transcript was printed out with large margins on either side of the text and numbered lines. The coding and analysis followed the process for Interpretative Phenomenological Analysis to consider patterns and themes

in the data (Smith 1996, Smith *et al* 1999). The transcript was read carefully and notes of subordinate themes or important issues were made at the right side of the text. This process was continued through the whole of the transcript in this manner to generate an expansive set of notes and comments, drawing associations, ensuring that the connections drew upon the original words and phrases used by the participant. This exercise was repeated whilst the digital recording was replayed so as to ensure all subtleties from the spoken word were included and that nothing was missed. Reading and analysis was an iterative process considering all the subordinate themes until no more could be found. These sub ordinate themes were logged in a separate document with reference to the source and extracts to support this i.e. participant and the line number was noted

3. Emerging themes: Returning to the transcript and using the left hand margin on each page notes were made of any emerging sub themes (see example noted in appendix E). This was done through taking the initial notes and combining them into relevant phrases ensuring that links were kept with the words and phrases as stated by the participant. This followed an iterative and logical process through the whole transcript ensuring that all subthemes were supported with reference to the individual phrase or sentence used.

4. Clustering of themes. Further, reading and rereading of the transcripts was used to inform connections and clustering of the themes mapped to the earlier sub themes and supported with phrases from the participant.

5. Superordinate themes. The transcripts were revisited with the subordinate themes to consider if these could be condensed into superordinate themes for each participant. These themes were organised into groups which captured the participants' major concerns about pain and living with pain and categorised as superordinate themes. As in stage 4 they were again mapped to phrases and words identified by line number to connect back to the original sources within the transcript. Thus a table of referenced superordinate themes was produced for each participant and are described in chapter 5. These superordinate themes for diary and interview transcript were

combined (Smith & Osborne 2008: 73). Subordinate themes were thus grouped with each other using the analytic process of IPA.

6. Next Participant: This iterative and interpretive approach was repeated with each participant's diary materials and transcribed interview before proceeding to the next participant's data. Each subsequent transcript was considered as a completely separate entity with its own terms and issues thus preserving the idiographic standard required of the IPA process. It was important to try to 'bracket' or put aside and ignore the themes from analysis of previous participant data so as not to contaminate the process.

7. Across Participant Analysis: The final step involved looking for patterns across the superordinate themes to find similarities or convergences between participant experiences and to consider apparent meanings keeping the participant's account and the researcher's interpretation clearly distinguishable in the narrative. Once each participant had clearly identified superordinate themes based on their understanding as identified in the transcripts they were grouped together for consideration and relevance across all the transcripts in the data set. After re-reading the transcripts, it was apparent that more of the superordinate themes were common to all participants than had initially been thought. This is not to identify these older people as a homogeneous group just that they had more in common because of their diagnoses and prognoses. The overarching or major themes which this produced are described in chapter 6.

4.8.2 Role of the PPI (lay advisor group)

The study was supported by a very competent local PPI (personal and public involvement) group in the development, ethical approval and conduct of this study. The design phase involved the consumer research panel³⁰ (Collins & Ahmedzai, 2005; Collins & Stevens 2006). This group comprises 35 former and current cancer and palliative patients and carers. This group provided feedback on the developing

³⁰North Trent Cancer Research Network Consumer Research Panel <http://www.ntcrp.org.uk/>

research project from concept through to data analysis and proved an invaluable resource to the study. The help from the PPI group was exhaustive, and prior to commencement of the study, this included reading the protocol, advising on the development of a lay summary for the patient information sheets, proof reading and commenting on the research proposal prior to submission for NHS Ethics Approval via the Integrated Research Approval System (IRAS).

Additionally, several of the transcribed interviews³¹ were reviewed by a third party (members of the NTCRN CRP). This was helpful in confirming the early theme development and offered some external verification of the process of analysis (Anfara *et al* 2002, Onwuegbuzie & Leech 2007).

4.8.3 Establishing Rigour, Quality and Validity of Data

Yardley (2008) identified four key factors in relation to the establishment of rigour or goodness in research: thorough data collection, depth/breadth of analysis, methodological competence/skill, and in-depth engagement with the topic. However, establishing rigour and robustness in qualitative research may be challenging as researchers are dependent on the paradigm, methodology and purpose which can determine the criteria and terminology (Stige *et al* 2009). Lincoln and Guba (2000) urge caution when considering how to determine the quality of qualitative research and identify four areas when considering the rigour and value of qualitative research. These four areas of rigour include truth or value (credibility), transferability, dependability and confirmability, which are now considered.

Credibility

In declaring credibility the researcher asserts that the research which has been undertaken has truth and value; that it is original and may be beneficial to others (Cutcliffe & McKenna 2002). In identifying a topic that has resonance with an apparently under researched area, older people experiencing cancer pain, the

³¹ All data was anonymised to remove any potential identifiers of either the participant or their place of care

researcher has determined that the topic has credibility and value. The older people, the participants in this study, determined and added value to the study through their participation in the study and their expression of lived experiences. Credibility might also be considered as determinable by the impact it might have on the body of knowledge, and potential consequent effect on care, of older people living with cancer pain.

Credibility could also reflect the accuracy and thoroughness of the participants reports, of their lived experience, which it sought to extract from the diaries and interviews. This was enhanced by the use of digital audio recording and speedy transcription (Tuckett 2005). Using members of the NTCRN CRP as a 'critical friend' in the research design, protocol development, ethical review and analysis (of anonymised transcripts) added to the general credibility of the development of this study. Using COREQ (the Consolidated Criteria for Reporting Qualitative Research, Tong *et al* 2007) as a guide also ensured that the research met the requirements of good qualitative research, an auditable process also intended to secure dependability and confirmability.

Transferability

Transferability refers to the potential for research to be generalisable to other contexts. Given that this is a small qualitative study the potential for generalisability to other contexts or situations is limited; however, transferability can be achieved through thick description of data (Lincoln & Guba 2000). Transferability may also refer to the value or contribution to existing knowledge and practice. Smith *et al* (2009) suggests that through gaining insight into the individual one might gain insight into the whole. Broad generalisations from this study are not possible, but Reid *et al* (2005) suggested that general understandings across accounts and subsequent 'analytic commentary' may lead to useful insights and future research. It is anticipated that the data provided by the participants in this study will illuminate areas for future development and research which may benefit individuals and organisations in the planning and delivery of care for older people with cancer pain.

Dependability

Dependability is similar to reliability; Guba and Lincoln (1994) emphasise the close links between the two suggesting that one informs the other. Dependability also refers to the clear and reliable approach to data collection which would enable another researcher to reproduce the study. This requires the researcher to be clear about the procedures and methods used in the study. Reporting in detail what was done, the methodology, development of process and methods of data analysis, should enable another researcher to repeat the study, if not obtain the same findings. There should be an auditable trail of research activity to achieve this data processing and quality guidelines for undertaking qualitative research were used to inform the development and conduct of the study (Tong *et al* 2007, Smith 2011, Booth *et al* 2014). A summary is provided in Figure 8.

Figure 8. Quality Criterion & Provision Made by Researcher informed by COREQ (Tong 2007)

Credibility	Transferability	Dependability	Confirmability
Positioning of the researcher & originality of research topic (in preface and chapter 1 & 2)	Potential for repeat of study.	Documented support of supervisory team, NTCRN CRP, clinical colleagues and peers	Digital audio records of interview and rapid transcription.
Verbatim transcription	Detail of methodology and process & auditable research trail	Detail of methods and analysis	Third party confirmation of emergent themes
Structured approach to analysis and theme development	Detail of recruitment process and purposive selection	Detail of recruitment process and purposive selection	Audit of research process.
Keeping close to participant's lived experiences	Discussion of interpretation and limitations	Detailed writing up of whole process	Reflexive and critical approach to undertaking research.

Confirmability

Confirmability is the extent to which the research methods and findings can be agreed or endorsed by others. Endorsing the methodology and findings through the iterative process of IPA, using a third party (supervisory team, peer discussion and members of the NTCRN CRP), to agree the validity of methods and emergent themes supports the

confirmability of the research. The researcher also needs to be aware of and address any potential for subjectivity or bias in the interpretation and presentation of the findings. Judicious use of extracts from the interviews, field notes, reflexivity in the research process, being critically self-aware and acknowledging limitations in self and the methodology are also important criteria for confirmability (Miles & Huberman 1994).

A rigorous approach was taken to data collection in attempting to apply the diary interview approach. Using the diary helped to gain access to some of the thoughts of participants and gain proximity to the experience of the participant when interviewing. The depth and breadth of the analysis enhanced the rigour of the superordinate themes for each case. Themes and superordinate themes were documented in proportion to their representation in the data and between cases to ensure trustworthiness of findings.

Rigour was further established through the detailed and iterative processes of analysis following the steps outlined earlier in section 4.8.1. Caution was taken to avoid making interpretations without sufficient supporting data. As research student and novice to IPA, supervision sessions and peer support from other qualitative researchers and the NTCRN consumer research panel members were used to ensure methodological and procedural rigour and credibility. Members of the consumer research panel also read several of the anonymised transcripts to independently validate the theme development process. The in-depth engagement was also facilitated by the thorough approach to recruitment, process of engagement and active listening. The whole process, in following IPA, demonstrated clear, transparent and reproducible application of the method. The quality of the findings, though not generalisable, support the premise for this study of person centred research.

4.9 Reflections on the methodology and procedures

4.9.1 Reflections on the recruitment process.

As discussed earlier, in sections 4.6.3 and 4.6.5, the recruitment of these participants was not easy. In retrospect, recruitment could have been more overt with the health care professionals in the various teams. For example laminated posters could have been developed for the MDT members to use with the potential recruits. Other professional groups such as the GPs, district and community nursing teams could have been approached. Organisations such as the hospital based cancer treatment centres could have been accessed. Charities and public organisations such as Helen's Trust and Age Concern might have been able to aid in recruitment. A more direct approach using media such as newspaper advertisements could have been considered.

The reasons why some participants refused to participate were logged. However, a more systematic approach should have been established at the start of the study for the MDT members to log all attempts to recruit and reasons for refusal (Petty *et al* 2001).

4.9.2 Reflections on the data collection methods

The diary was not as successful as hoped. The idea of having the diary inform the interview was good and led to greater amounts of varied data from each participant. Using a diary was to ensure that the participant led the discussion in the interview. Interviewing people who are ill or fatigued is not easy as they may become easily tired. Hence to obtain sufficient rich and varied data more, but shorter, interviews might be considered if this study were to be redone.

The participants knew the researcher was a registered nurse; a researcher undertaking the study. This was stated at the preliminary contact, before obtaining consent. Whether self identification as a health professional was an enhancement or an impediment to the obtaining of data is clearly worthy of future consideration. However, one of the advantages of being a health professional was the skill to prepare for dealing with distress, if it occurred in any of the interviews. If a participant had

been distressed they would have been supported by the researcher and, with their consent, would have had their supporting health professional informed.

Reflection on the researcher's influence on the research process was constant during the study. Removing any personal influence over the methods used was impossible. Inevitably, with unfunded doctoral studies, research ideas and methods are influenced by the researchers' own values and agenda. Indeed, recognition of the effect of a researcher and her sway in collecting and interpreting data in the context of personal and professional experience are potential strengths of qualitative research (Barbour 2003).

4.9.3 Reflexivity and Data Analysis

Being reflexive in qualitative research is part of establishing trustworthiness and acknowledging the effects of a researcher in terms of influencing the outcome of a study. Reflexivity can be examined specifically in terms of the actual and potential personal, interpersonal, institutional, pragmatic, emotional, theoretical, epistemological and ontological influences on research and data analysis (Mauthner & Doucet 2003).

With the benefit of hindsight it is possible to consider the influences that the researcher may have had on the development of the research. The emotional response to the descriptions has undoubtedly shaped some of the interpretations. The emotional response was bound with personal and professional experiences and observations. Locating the researcher as a former pain nurse made listening and empathy more achievable.

The personal experiences of the researcher as carer and professional led to the development of the topic of interest, pain, older people and cancer. The academic role of the researcher and her biography has informed the development of the world view, appreciation of knowledge, theoretical perspective and methodology. Thus, these influences may have obscured some of the entire, detailed and nuanced individual accounts and led to a partial and potentially biased representation.

4.10 Summary

The experience of pain in older people with cancer was not exclusive to any particular group or location. Setting early limits to particular cancers and a single location adversely affected recruitment. The timescale of the study prohibited including many more organisations or lengthening the recruitment time. However, more areas should have been included as potential recruitment sites at the outset. Thus, this ideal of generating data in a variety of settings was only partially fulfilled.

This chapter has attempted to clearly set out a clear and detailed account of how the research was designed, applied and modified in response to adversity and taking account of the research aims. The effected changes were wholly pragmatic and practical and this account articulates an auditable trail of their application and how this affected the data analysis. In chapters 5 & 6 the descriptive and interpretative findings will be presented.

Chapter 5

Findings 1 - Descriptive Analysis

5.1 Introduction

This chapter presents the data from the diaries and interviews as a descriptive account, a vignette or 'case' of the unique subordinate themes for each participant following the methodological approach of IPA. To reflect the iterative process of IPA these data will be first presented in the form of narrative, a synopsis of each participant's story. This method utilises the first element of the double hermeneutic approach to the data, where the researcher attempts to make sense of each participant also trying to make sense of their own individual experience. Approaching each person's data as unique and valued respects the iterative, dynamic and holistic view of the 'life world' for each participant (Smith & Osborn 2008). By engaging with the lived experience through diaries and interviews some insight may be gained into the individual's subjective world view. The overarching themes and concerns raised from the interpretative analysis will be presented in the next chapter

5.2. Descriptive analysis

Eleven participants were initially recruited to the study but only nine older people completed interviews; two participants died suddenly. All were white British, and with one exception English was their first language. Many others considered participation but declined, the known and potential reasons for this were discussed in chapter four. All nine participants were initially invited to complete diaries and although all agreed to this part of the study, five diaries were not completed at all and some of the completed diaries were more detailed than others. The diaries kept by participants 04 & 08 had several lines describing each day whereas participants 1 & 10 only wrote single short sentences. Thus, the diaries were not all equally complete or informative for the study. It should be noted that in addition to the diaries, these individual

descriptions were informed by the researcher's field notes and reflective diary. The data are presented in chronological order of recruitment reflecting some 18 months of recruitment and interview activities.

The stages of analysis followed the principles of IPA (Smith & Osborn 2008) and were guided by the methods detailed by Willig (2008: 57) as detailed in section 4.8.1. Thus, a clear and systematic approach was taken to theme development and the clustering of subordinate themes to form superordinate themes for each participant. Examples of the iterative process of data analysis to develop the subordinate themes and themes are included in appendix D & E.

5.2.1 The Older Participants

Table 4 summarises some of the data for the participants who completed the study. For each participant there were contextual and biographical narratives which were fundamental to appreciation of their unique lived experiences of cancer and pain. Underpinned by the methodological and theoretical basis for this study, the findings are presented as a narrative summary of superordinate and subordinate themes with references to their origin, by line number and participant number, in the original transcripts.

Table 4

Participant	01	04 ³²	05	06	07	08	09	10	11
Pseudonym	Ethel	Robert	John	Eric	Fred	Dougie	Ernest	Bob	Hilda
Age & Gender	82 F	68 M	67 M	72 M	83 M	84 M	72 M	68 M	88 M
Diary Completed	Yes	Yes	No	No	Yes	No	No	Yes	No
Location of Interview	Home	Hospice	Home	Home	Home	Home	Hospice	Hospice	Hospice
Recruited Hospice	1	1	2	1	1	1	3	3	3

Participant 01 Ethel

Ethel lived alone in a small warden controlled bungalow in an urban community not far from where she was born and had spent most of her life. She clearly had roots in this community which she had never left. The initial contact was made at the hospice but she wanted to be interviewed in her own living room. She was a widow, 81 years old, who had attended the day hospice for about 3 months³³. She looked forward to all visits, including one from a researcher. She had planned for her warden to call just after the researcher arrived to give her an excuse to ask her to go if she did not 'like

³² Participants 2 & 3 died before they could complete the study.

³³ Some hospices limit the amount of time palliative services, such as the day hospice, can be accessed.

the looks of her'. Ethel liked her weekly visit to the hospice and found solace in access to the 'centre', a community room adjacent to the warden controlled buildings, for all which was open every day except Saturday. She did not get any visitors at all on a Saturday. She enjoyed seeing her son, daughter and grandchildren on Sundays.

Ethel's superordinate theme was her need to maintain independence. Proud of her independence, she acknowledged her diagnosis but wanted to dismiss much of her problems as related to 'old age'. She talked of the cancer, which she acknowledged had spread to her spine, as if it was a mechanical back injury. This deflection of her diagnosis and prognosis appeared to give her comfort and some acceptance. She wanted to be useful to others, particularly her children and grandchildren, and her inability to help and support them caused her much distress.

The subordinate themes which Ethel described included

- independence through adapting and coping
- reluctance to acknowledge cancer as the cause of any symptoms
- reluctance to use analgesia
- identifying self through history and social encounters

Adapting and coping to manage living was something which Ethel needed to do; she wanted to stay independent in her own home. She also felt it was important that she could tell people about how she was coping.

'It's in my back, you know...I can live with it...it's not agonising all the time.'

(line 22, 01)

This bold statement towards the beginning of the interview described her desire for independence and reluctance to let the pain interfere with her life. This was reinforced a few moments later when she said:

'You can't let it get to you or life would not be worth living...would it?'

(line 46, 01)

This request for confirmation revealed briefly that she was aware of her prognosis and coloured much of the later conversation. She had adopted various forms of distraction to help keep her busy, the main one was walking. However, any physical activity seemed to cause her much distress particularly activities where she had to bend such as making the bed. She gave a particularly harrowing account of putting a bed sheet on her mattress:

'Yes I just have to pace myself, you know. I would be changing the bed then and er when I have done so much of it I have to come and sit down. ...until the pain goes and then go back and finish it and do a bit more... and that is what I have to do...'

(line 42, 01)

Ethel had to rest for an hour before she could return to finish the procedure. She also made meals but would have to do this in stages because of the pain of standing over the kitchen surfaces; thus meal preparation might take many hours (line 77, 01). The way she managed her laundry was equally daunting for her. She had to position a chair near to the laundry door entrance to ensure she could navigate the steps (line 187, 01). She was reluctantly acknowledging her limitations 'I am struggling now' (line 96, 01) but seemed determined to continue to find creative ways to address the challenges of her painful back. Many of the things she did and the way she structured her activities were about being occupied and being useful to others. The worry of being a burden to others was also a major contributor to this desire for adaptation and independence (line 179, 01).

Ethel chose not to present the cancer as the main cause of her pain. Despite identifying her back as the place where she experienced most pain and also as the site of her cancer (spinal metastases in her thoracic spine) she preferred to discuss the pain

in relation to some other mechanical cause 'I've got some sort of broken back...' (line 26, 01) or in relation to her chronological age:

'...I think was arthritis or age related pain not from my illness...'

(line 55, diary 01)

The cancer had made her identify herself as old and she clearly preferred to use this and other diagnoses to deflect or avoid mention of the cancer:

'I am getting older you know...'

(line 34, 01)

Ethel also related that her activities, when working and doing decorating as a younger woman, must have contributed to her back pain: 'I am paying for that now' (line 103, 01). Later when talking about her pain she said:

'I don't think that's really related to my illness'

(line 251, 01)

Ethel did not like taking analgesia. She was saving her analgesia for when she really needed it:

'I can cope with pain you know...I don't want to (increase the analgesia)...'

(line29, 01)

Ethel also disliked the effects of analgesia: '...cos that made me really ill' (line 31, 01). She found her sleep frequently disrupted by pain 'I get up and make myself a cup of tea...I take 2 paracetamols...I wouldn't like to take any other pain killer' (line 113, 01). But, then she retrospectively played down the pain suggesting that she might have been woken by the daylight. Her opinions of the use of analgesia were mixed she did not like taking too much, 'it affects your bowels...but, its good stuff it is marvellous

stuff' (line 125, 01). The reluctance to take analgesia was also commented on in the diary, where she 'wanted to save the stronger one for later' (line 61, diary 01).

The pain affected her more when she was alone and in the absence of 'company' she was more susceptible to experiencing pain (lines 27, 43, diary 01). After the physical pain the thing she appeared to dread the most was loneliness. What she valued most was human contact and social encounters. The regular weekly visits to the day hospice and the visits of her children and grandchildren were of great importance and made her day full. She described her desire 'for a bit of company' on Saturdays when she usually had no visitors and the old people's day centre was closed.

'(These are) awfully long days...'

(line 70, 01)

Ethel appreciated having children and grandchildren visit but after they left she would feel exhausted, 'but it's a nice tiredness' (line 43, 01 diary). She also greatly valued visiting the day centre:

'talking to people and having a laugh...forget your pain...push it to the back of your mind...'

(line 140, 01)

Her belief in the benefits of visiting the day hospice was emphatic:

'...it must do me good, it does, I know it does'

(line 145, 01)

Though, the pain of travelling, having to sit in uncomfortable seats in transit to either the hospice or other health care venues was tolerated and made her 'determined' (line 180, 01) to cope with the pain.

Ethel needed the contact of other people but she wanted to give a more complete, almost biographical picture of who she was, beyond having cancer. Much of the conversation was prefaced with references to what she used to do and what things had been like for her as a younger person. It was as if Ethel needed present an earlier version of herself; to understand and appreciate her as she was now required an understanding of the former Ethel.

'I regret not being able to do...things with my grandchildren...'

(line 204, 01)

This was a lone reference to loss of ability and identity, as a grandmother, that she had experienced through her diagnosis. This was in stark contrast to the many other positive comments she made either about her identity past and present, through achievements as a wife, mother and homemaker, which to some extent she was maintaining in supporting her children with occasional child care, sewing and knitting. She also made references to things she had done and could not do now but dismissed these. Regarding holidays she had enjoyed some with her late husband but now thought they were 'overrated'.

Despite describing herself in context with her former self, the older Ethel dismissed as irrelevant the things she could no longer do.

'I'm not bothered you know, It's too much of an effort...'

(line 306, 01)

There were several other references to not being 'bothered' as a catch all cover up for the loss of function or opportunity she now experienced.

Participant 04 Robert

Robert was an enigmatic character, large in personality, a 68 year old, retired scientist and engineer. He had been diagnosed with liver cancer about 5 years prior to the

research interview. His wife had been diagnosed with advanced dementia at the same time as he had had major surgery on his liver and so she had been admitted to a specialist nursing home against his family's wishes. After the death of his wife he had moved, from his large family home to a smaller one, to be nearer his sisters, who provided much of his care.

Robert was very independent and still drove a car most days but clearly longed for the professional person he once was and made frequent comparisons with what he did and had now with his pre cancer activities, hobbies and general lifestyle. He was interviewed, at his request, at the day hospice in a private room. Much of the discussion was around the solace and comfort he found in food and cooking. He did not like his analgesia because it either made him nauseous or took away his appetite. He balanced eating and pain relief. He wanted to talk about the present, pain, food and relationships and related these to and contrasted them with his former life and who he was. But, there was no talk of the future at all. Only at the end of the interview he made brief mention of the four daughters with whom he no longer had contact, a moment of reflection and possibly regret before he ended the interview.

The superordinate themes for Robert were independence and control. Through describing the way he accepted and adapted to his new life with untreatable cancer Robert was acknowledging his unique biography and identity. It was difficult to separate his pain experience from the expression of his daily living and his biographical accounts. Robert repeated references to his independence and capability though describing driving his car and in undertaking household chores:

'I don't have any home help or nothing.'

(line 231, 04)

Robert also described briefly 'losing confidence' when using the bath or shower (line 224, 04) and how he washed at the sink instead. He conceded that he might need help in the event of an emergency and shared that he subscribed to a local authority telecare scheme which provided an alarm pendant. This was acceptable for the gadget

loving Robert because it gave him the 'feeling of independence' (line 247, 04). He described mostly enjoying visits from his family but this was not always experienced positively. Of one relative he said 'she's always in there sort of doing things...and tidying up after me', suggesting that he resented having others to assist him with daily tasks.

The subordinate themes which Robert related included

- dismissing his symptoms,
- blaming treatment for his pain rather than the cancer
- dislike of analgesia
- metaphor (food and gadgets)
- loss of identity

Robert was dismissive of having cancer he presented the independent and capable during the interview.

'I do not have much pain at the moment ...'

(line 155, 04)

This contrasted with the content of his diary where he made frequent reference to 'feeling rough', spending time 'in bed' and 'feeling unwell'. Robert was reluctant to admit that his life had changed but his references to all the changes he had had to make conflicted with this projection. Early in the interview he cited the major cause of his pain and health problems as due to diabetic neuropathy. The 'self', whom Robert presented, was of someone who was both intellectually clever and practically able. 'I've always been pretty active you know...' (line 98, 04). This was the preface to a short description of his working career and abilities where he described an interesting and challenging career in engineering and computer systems. He also referred to his recent acquisition of a shed to reinforce his continued ability at DIY, and future plans, despite the cancer (line169, 04).

Robert made some nostalgic nods to his former his former self in a few of the phrases he used such as 'I used to turn my hand to anything...' (line 178, 04). He presented contrasting extremes of ability and within a few moments described himself as able, an example of this was where Robert said the pain caused 'no problem...' (line 190, 04) and then said it stopped '..virtually everything...' (line 200, 04). These statements could not both be true, to endorse his capability, Robert, then described his driving ability.

Robert presented alternatives to the cancer as causes of his pain and was angry about these. He had considerable anger which was directed at the various treatment regimens he had been given over the years starting with his diabetes treatment through to the recent renal dialysis he had undergone. The surgical sites where the medical team had attempted to create an arteriovenous fistula were causing him some distress as we spoke. He described the apparent damage to his circulation because of the fistula and subsequent pain and problems in his hand (line 55, 04). He described the treatment as 'c**p' and 'year after year, the rottenness of the tablets...' (line 63, 04). He also had low expectations of any future potential treatments (line 141, 04).

More comments about side effects appeared to support Robert's concerns and reluctance to take any more tablets. In sharp contrast he then said his tablets worked very well and 'allow me to...do the things I want to do' (line 157, 04). He contrasted his heavy commitment of time to having dialysis with the benefits (line 185, 04). He also described recent positive experiences of physiotherapy and some of the exercises he had been given (line 147, 04).

Analgesia was a last resort. Robert described the severity of the pain in his shoulder but was a very reluctant taker of analgesics despite knowing they relieved the pain.

'The side effects of those tablets are absolutely horrendous.'

(line 67, 04)

Robert also seemed to appreciate that on occasion he might need to take them. One particular experience noted in his diary related his taking a rather large amount of

analgesic. He 'dosed himself up over the weekend' (line 75, 04) and slept for 26 hours, he did not leave his bedroom for over 36 hours. He was evidently good at forward planning because he had a supply of bottles of water at his bedside just in case. This is one example of Robert presenting himself as very organised.

Much of the interview was peppered with metaphor either technical or food related, reflecting his enormous affinity with eating. The range of metaphors used, in which he often referred to the disease in the third person, reflected his personality and the person he wanted to project. He clearly had a sense of humour and was also trying to make sense of a very complex situation. The objective and technical Robert described his dialysis as being 'plugged in' (line 55, 04). He described his kidneys as 'just ticking over' (line 85, 04) and the dialysis as 'just doing a bit of recycling (line 95, 04). The severity of his pain was reflected and reinforced throughout the interview with mention of food, either what had been cooked or when he could not eat. The pain seemed to be worse and in need of treatment if his eating or appetite was affected:

'...pain curbed my appetite...'

(line 218, diary 04)

Alongside food, his next favourite pastime appeared to be sleeping and having a new comfortable bed was a 'vast improvement' (line 324, 04).

Much of the pain related to his loss of identity, possessions (with moving house) and loss of friends. Some of the emotional trauma he attributed to his cancer but much he blamed on the loss of his wife and having to relocate to be near to caring family members (line 546, 04). Alienated from family, his daughters, and distanced from many of his old friends, through relocating to be nearer his sisters, had caused him distress and cost him much of his former identity alongside having the cancer. He seemed to talk about his current life and identify himself through his desire for and use of technology to support his independent living. Robert liked his 'gadgets' and anything technical which could support his independent living was of great value and was significant to him. He had things to help him with his daily living to reduce the

workload including a 'condensing washer' which removed the need to put clothing to dry. However, he had to get rid of a lot of 'amenities' when he had moved house (line 334, 04).

Participant 05 John

John was a 67 year old, retired miner, who had had many hobbies, including pigeon fancying, gardening and rugby. He had wanted to be a professional rugby player in his youth and despite having 'a strong liking for the ale' (his words) he was proud that he had maintained a slim figure. He chatted amiably and dismissed the cancer as 'one of those things ...' He made much of his ability, as a strong man and former miner, to bear injuries and tolerate discomfort. He did not like having to take any medication and was a reluctant visitor to the GP, hence his late diagnosis and poor prognosis from cancer of the prostate which had sadly spread by the time he was interviewed. He had a poor short term memory and liked the idea of a diary but he did not complete more than to write his name and the date on the first page. His account of his pain was not described as such, rather he mostly talked of comfort and loss. He was particularly mournful for the loss of his greenhouse and inability to set his onions.

John's superordinate theme was independence with subordinate themes from the interview:

- presenting himself as tough and independent
- contrasting selves as impervious to suffering and sensitive parent
- grief for his former self.

John had been a 'tough miner' and this was the person he mostly described. At the beginning of the conversation John was clearly in pain 'in the centre of my back' (line 37, 05) and constant pain had become his norm (line 318, 05). He was expecting someone to come and 'sort it out' (line 66, 05). In the next breath he played this down by saying 'it was only illness' (line 42, 05), was he implying that he would recover. However, he was clearly afraid of both the pain and going into hospital and losing his

independence. When talking about his recent hospital stay he had thought he might die (line 49, 05). These contrasting perspectives on his pain and the experience of illness continued throughout the conversation.

The next part of the conversation was largely about the strong and capable John, the fighter (of pain) and was interspersed with pugilist metaphors and references to his remembered physical fights as a young man.

‘I’m what you call a fighter; I fight things.’

(line 131, 05)

John presented himself as a former miner who had lived a ‘hard tough life’ only interspersed with drinking which was his ‘main hobby’ (line 160, 05). This had been part of the camaraderie of the mining community in which he worked and lived. He had also been an amateur boxer and played rugby league, both of which he was very proud. He could sort out the cancer just as he could ‘sort somebody out’ (line 457, 05) and he was not a ‘sissy’ to take analgesia (line 411, 05). The theme of being tough continued later with description of how John used positive thought processes to control his pain ‘by telling it to b*****r off’ (line 221, 05) and saying ‘I can control (the pain)...’

John contrasted this tough persona quite starkly with descriptions of his former role as single parent and now grandparent. John presented a different version of his former self, the husband, father and most importantly (currently) the gardener (line 168, 05). His family and particularly his children had been very important to him (line 510, 05). The importance of role and responsibility became the focus of his life and presentation of ‘self’.

John related his positive memories of having been a miner and how this was a major element of his social life. He had frequently visited the public house, with his fellow miners, and ‘used to like a drink’ (line 109, 05). He could no longer get to the pub and he was not supposed to drink alcohol with his pain medication. He back tracked a little

to suggest that his family responsibilities were greater than his favourite pastime of drinking (lines 176, 348, 05). He wanted people to know that he had substituted gardening for drinking. However, John's comments did not only convey adaptation they clearly implied loss.

The grief John felt for his former self was strongly evident. He mourned for his former capable independent self. The pain was affecting John's mobility and he reluctantly acknowledged that he now used a stick. There was also some inference of resignation to his reduced mobility (line 71, 05). He was temporarily staying in a nursing home and was missing his independence (line 79, 05). This was part of an optimistic thread where he talked of 'when I go home'. His distress about his relocation was later confirmed when he talked about his uncertain future in reference to whether he would return to his bungalow (line 234, 05).

John down played this loss by saying that he wasn't bothered, several times (lines 114-116, 05). He implied his age was to blame 'my body is telling me to stop...' (line 122, 05). However, he was concerned that activity would aggravate the pain (line 127, 04). John had also conceded to the use of his mobility scooter (line 267, 05) which he needed because of the pain in his back on walking.

A discussion of gardening became quite animated as he was clearly missing both his ability to garden, because of the pain, and the loss of the facility to do so (line 185, 05). The discussion of gardening was further tinged with sadness and distress because his greenhouse had been sold by his relatives. Living alone, the facility and strength to garden had become his focus for living and the cancer and pain had deprived him of this (line 212, 05). Old age was probably to blame as well as the cancer (line 241, 05):

'...but I'm still fit enough to look after myself...'

(line 355, 05)

Much of John's narrative of grief related to loss, loss of mobility, loss of scooter, loss of greenhouse, loss of pub or social life and loss of his independence generally. But, John was mostly upbeat in all he described of the present and surprisingly optimistic for the

future including visits to the hospice day centre (line 379, 050) and going home (line 355, 05):

‘I want to get back to my own place.’

(line 280, 05)

Participant 06 Eric

Eric, aged 70, lived with his wife in a semi detached house. They had lived for holidays and golf both of which they had foregone now because of Eric’s limited mobility and ability to travel. His cancer had spread to his legs and affected him ‘like a stroke’. His wife had become his carer and he had a hoist to help him into a chair or on to the bed. He and his wife recounted their poor experience of council and social services. They had worked hard and saved hard. Indeed, after waiting many months for adaptations to home and car they had found they were ineligible either because they were too old³⁴ or because they had savings.

The conversation was largely led by Eric who was much aggrieved about this presented inequity of services which he felt were targeted at those aged under 65. Much of Eric’s pain had related to positioning because of his immobility and the distress he had experienced appeared to be related to what he presented as the insensitivity of service providers. The exception to this was the ‘wonderful’ day hospice. He now had a car and an expensive motorised wheelchair which he and his wife used to frequent parks, shopping centres and as many flat wheelchair accessible venues as possible. He took the diary but later stated that he did not wish to complete it for the study.

When asked about his pain, Eric described much of his current experiences through lengthy biographical accounts of his life. Biography was the superordinate theme accompanied by subordinate themes of

- adaptation to maintain independence,

³⁴ Motability the allowance for people with disabilities to have a car is not available for those aged 65 or older at diagnosis.

- hope,
- anger
- ambiguity towards the pain and treatment
- dislike of analgesia.

Eric was motivated to adapt and maintain his independence despite the pain. His major anchor was in trying to maintain something like his former life:

'...I was very active, living a normal life.'

(line 28, 06)

His recent loss of mobility caused him grief for his former self. His life had been very full with activities including travelling. He had had a motor home and travelled widely and regularly (line 664, 06). The grief for having to give up this was evident; not just the loss of the vehicle but the lack of contact with friends and fellow travellers was distressing.

Eric had felt that up to Christmas he was getting better:

'...of course I was wanting to do more and more, and I was, I was getting more and more... (independent)'

(line 84, 06)

The life that he had enjoyed and his inability to continue with the same activities caused him significant distress. Eric was keen to counter this with examples of how he had modified his house and in his use of an electric hoist and the introduction of a wet room. His safety was a big concern to him Eric was fearful that if he fell this could lead to him becoming a greater burden:

'I felt if I was to fall we'd be struggling.'

(line 102, 06)

Alongside Eric's desire for independence there were notes of optimism and hope. Eric took comfort in some of the words that he recalled from the oncology team 'I think you've got a window here... you've got a chance...' (line 445, 06). Perhaps he was grasping at small things but he recalled the smallest communications of hope. If Eric had heard any words or allusions of improvement or cure in his encounters with health professionals these were treasured and the people regarded with esteem and reverence:

'Seeing Dr X was like a breath of fresh air...'

(line 416, 06)

This was particularly poignant when he contrasted such positive experiences with his own knowledge of his diagnosis and prognosis and the occasional negative encounter with one of the professionals involved in his care.

Eric was also angry at times but this was not directed at the health care system. He related that most of the changes he had made to his home were at his own expense. In the initial part of the conversation he railed against the council and other authorities for offering no financial support to maintain independence either in the home or with the cost of transport. Eric was also particularly angry about the way Motability is funded because of the '...general unfairness of it...under 65 they get everything...' (line 240, 06):

'...if I'd been under 65...brand new car...'

(line 283, 06)

In contrast Eric was proud of the fact that he had been able to resource all the changes and adaptations he had made.

His understanding of, and ambiguity towards, the cancer and pain were evident. He stated that the cancer in his spine had caused his immobility (line 45, 06). However, he

fell ill at Christmas, with something unspecified, which he viewed as being a significant factor in his current inability to walk (line 56, 06). The cancer had spread but he did not wish to acknowledge that this was the cause of his immobility. The pain had not increased so he was saving the option of more radiotherapy for if his back became more painful (line 63, 06). He was also convinced that the radiotherapy could not help his immobility (line 76, 06). He expressed mixed feelings about having more radiotherapy treatment and implied that, though there was a very small chance of regaining his ability to stand and transfer, he did not wish to take this chance:

‘...whether I should have it (radiotherapy) or not. Or save it for when I’m ...in severe pain.’

(line 79, 06)

Eric made several references to saving his radiotherapy for severe pain (line 516, 06). However interestingly he seemed to think that the radiotherapy had caused his pain. In reference to his low back pain he said:

‘...they were saying oh radiotherapy, this is how that came about’.

(line 511, 06)

Eric expressed his dislike of taking analgesia and then described all the times he needed it. But, weight bearing had become excessively painful for which he needed to take oromorph (oral morphine) (line 66, 06). Eric felt his arms had become stronger to compensate for his lack of functioning legs (line 92, 06). However, he could no longer use the hoist to aid his transfer because he was not as strong as he had been (line 114, 06). He used the oromorph when the pain was ‘tremendous’ (line 528, 06), unfortunately he experienced this when sitting or driving for long periods. He justified his reluctance to take oromorph, citing one incidence of having retained a large volume of urine, for which he had mistakenly taken analgesia thinking it was the cancer pain (line 495, 06). It was evident that Eric took pleasure in describing something that was not cancer and yet had caused him so much pain.

Participant 07 Fred

Fred was a man who gave the impression of eternal optimism. He was introduced as Frederick by the hospice nurses and was quick to point out that he did not like this and preferred to be simply 'Fred'. He asked to be interviewed in his home and related his limited availability for interview due to a busy social life. He was an 83 year old widower and lived alone though at the time of visiting he had both daughters staying at his home but not present during the interview. Fred was a church goer and much of his social life revolved around the local Methodist church. He found much solace in his faith and did not talk about his pain though his diary entries clearly related his daily and nightly discomfort. Fred wanted to tell me about *who* he was and the life he had had. His life experience, his life as a hardened professional soldier, rather than his pain was what he wanted to relate.

The superordinate theme which Fred presented was that old age rather than cancer was to blame for all of his symptoms including the pain:

'I'm just getting old and my body's getting worn.'

(line 14, 07)

The conversation was interspersed with similar remarks (line 637, 07) Fred preferred to describe his pain as due to 'old age'.

The subordinate themes which Fred described related to his dismissal of the cancer. He described:

- the story of his diagnosis and his life story
- grief for his former self
- dislike of the word 'pain'
- loss of confidence

Fred told the story of his diagnosis and prognosis, interspersed with references to his career and his marriage. By way of explanation he stressed the way illness was

'something to get on with' in the forces. He told of the jokey way he and his soldier colleagues had referred to cancer:

'He's gone west (got cancer)...in the forces you tend to be ...not very sensitive to things.'

(line 549, 07)

Fred had been a tough soldier and was keen to introduce his resilience early in the conversation.

'...they terminated my treatment...I'm still here...'

(line 19, 07)

Fred described his survival despite chemotherapy treatment having stopped because he was told he was 'too weak' to have any more (line 20, 07). He was very proud of his apparent staying power: 'Against the odds I pulled through' (line 58, 07) but acknowledged that he was absolutely 'worn out' (line 52, 07). The fatigue was clearly partially due to Fred's cancer but his account was of how he had had to be resilient to support his dying wife. He was clear that he did not fear dying and that his Christian faith would support him (line 577, 07).

Fred was grieving for his youth, his former self as a soldier and his wife. Fred had suffered much tragedy in his life, in particular his wife had died of cancer and he had witnessed her experiencing much pain (line 15, 07). Fred's account of his own diagnosis and initial treatment was largely contrasted with his memories of his wife's cancer. Fred's wife had been diagnosed with cancer after he had, and she had died within a year. The dying and death of his wife from cancer had been a devastating experience for Fred.

The word pain was regularly dismissed in the conversation. Several times Fred stated that he 'had no pain' (lines 6, 17 & 114; 07). This contrasted with the diary entries

which contained daily detailed descriptions of various pains and the statements from Fred about the various painkillers he took and the times he had to take them:

'I do take painkillers for pain.'

(line 118, 07)

Despite admitting that he had a lot of pain (line 119, 07); Fred attributed his need for pain killers as an 'addiction'. This need to take up to 8 tablets during the day and some in the night, Fred described as 'psychological' (line 137, 07). He was also in control of his emotions and described an experience when he was in hospital and needed to be calm and polite despite being in pain 'I don't get myself worked up...' (line 241, 07). The soldier, Fred, reluctantly used the word 'pain' and preferred to dismiss the 'pain' from his cancer or give alternative explanations for living with pain.

The experience of living with pain and the effects of Fred having been recently widowed were hard to separate. The pain Fred described in his diary was there most of the time however much of what he could not do was attributed to either fatigue or his lack of ability:

'Well yeah, I mean I wasn't allowed in the kitchen. My wife used to do all the cooking. I mean I might boil an egg, that was about as much..., but she used to do all the cooking. I mean I live mainly on chilled meals or frozen meals, but my daughter, I mean she's brought me a meal in now, put in the fridge for tonight. Two or three times a week she'll bring me a plated meal up, but other than [that] I usually get these frozen meals or chilled meals, because I'd be useless at cooking.'

(line 291, 07)

Fred had lost confidence in his ability to do things at home and to learn new things. Domestic chores had not been part of Fred's life and he had never cooked. He now relied heavily on frozen food or meals cooked by his daughters. His driving had

become more restricted, in terms of the distance he could travel, but he still went shopping occasionally for food and supplies (line 330, 07). However, the pain and the cancer meant he could no longer walk to the shops. His pain and lack of ability to walk very far meant his social life and activities were limited to 'if there's a seat handy...' (line 368, 07). He had also lost the confidence to go walking anywhere alone (line 372, 07). His social life involved attending various clubs and his local church however he could no longer remember the names of his friends and acquaintances (line 401, 07). Fred was concerned that the cancer had affected his memory and he was sad about this loss.

Participant 08 Dougie

Dougie was 84, he lived in an alms cottage owned by his former employer. He had been an international dog judge and his late (second) wife had owned a best of breed Crufts winner and had been a judge at Crufts. He had travelled the world and worked in many different jobs. His passion had been dolls houses and he had made these for his family, friends and local charities. He had one son from whom he had been estranged for over 40 years. He had step children and grand children from his second wife who were very attentive, frequent visitors. His travelling had been curtailed by the cancer but he was determined to go to his favourite gospel singing event in Whitby. He loved music and showed off his deafeningly loud new Bose speakers. His pain was in his chest from frequent chest infections and 'scarring' from the radiotherapy. He acknowledged that music and prayer were great sources of solace for him and he enjoyed planning his next day out or holiday which he would continue to do as long as he could.

The superordinate theme for Dougie was to blame other things than the cancer for his pain. This was the main message which Dougie projected. Dougie first introduced this to the conversation by blaming his hernia (line 9, 08). He then contradicted this by describing how his cancer had involved his bowel (line 27, 33, 08) and later when he talked of the pressure of the cancer (line 378, 08):

'...the hernia is right where the polyp is, which is malignant...'

(line 478, 08)

Dougie preferred to blame arthritis for much of his pain and limited activity (line 338, 08). Also, his cancer was not to blame for his current chest infection:

'There's nothing on my lungs, the x-ray it was clear...'

(line 425, 08)

The subordinate themes which accompanied this were issues of:

- coping
- identity as a tough and capable individual.
- dislike of analgesia
- grief

His apparent mainstay and coping mechanism was through music and shared his love of musical theatre (line 38, 08). However, it quickly became apparent that it was his appreciation, in particular, of Gospel music which gave him solace. He had grieved for his late wife and had found that his Christian faith, expressed through Gospel music and church attendance had given him much support:

'...I've been going back there ever since.'

(line 88, 08)

'I've never had a care in the world...wake every morning and say thank you'

(line 193, 08)

'I go to church every Sunday...'

(line 694, 08)

His motivation to attend a local Gospel festival was so strong that he had asked the team at the hospice if someone might be able to take him. He commented that his GP had offered to contact the local Red Cross to ask about transport.

Dougie described himself as a strong and capable man who had worked hard and had been very independent. His strength of character was clear, he was highly motivated and he described with fondness the efforts he had undergone to support local charities with fundraising and general support. He had recently done a sponsored walk for a heart charity (line 152, 08) and raised money for the local fire brigade charity (line 156, 08). In his working life he had been a respected individual; his former employer had created a job as chauffeur/handyman for him when he had been made redundant (line 854, 08). Dougie was used to using his hands creatively, an avid model builder. He had made tiny scale models of the furniture he had made during his working years as a carpenter. He had also looked after his dying wife and provided all her physical care including moving her (line 184, 08). He was proud of his versatility and listed many things that he could do or had learned to do, this included the housework which he still did (line 358, 08).

Dougie resisted asking for any help and when asked about family support he replied about his daughter, '...she's got enough on her plate' (line 388, 08). He had adaptations in the kitchen and in the bathroom to ensure he needed minimal help. He continued to present this image of the capable, independent and stoic individual. When asked about the possibility of a scooter he responded:

'...if I need one of them (scooter) I shall pack it in'.

(line 842, 08)

At his diagnosis with 'terminal cancer' Dougie said he had responded pragmatically to this telling the consultant:

'Never bother about anything you can't do anything about...

(line 174, 08)

The grief Dougie felt for his late wife and his former life were evident in the animated way he described their happy times together particularly when they had travelled and judged at national and international dog shows. The nostalgia in his narrative was evidenced by the way he changed the subject back to the 'good times'. He had filled his life with making things and he had tried to replace these with the skills acquired at the day hospice. He was particularly proud of his 'silk painting' (line 564, 08).

Dougie did not like painkillers, despite having a lot of boxes of analgesics on his small table adjacent to his chair (field notes/reflections):

'I never have took pain killers.'

(line 440, 08)

Dougie related taking analgesia to 'giving in'. 'It all starts up here' pointing to his head
Dougie continued:

'easiest thing in the world to sit down and say that's me done, its
keeping going that's the hardest part.'

(line 878, 08)

However, Dougie was clearly in distress with both his abdomen and breathing throughout the interview although he refused offers of any early finish to the conversation.

Participant 09 Ernest

Ernest was also a former soldier, a 'Sapper'³⁵, aged 72, who had latterly been a verger and church warden for the local church. He had been much travelled both in his

³⁵ Sapper is the nickname for a former member of one of the British Army's engineering regiments.

military career and on holidays. He had 'horrific' diabetic neuropathy which was 'caused by the treatment' for myeloma. He felt quite aggrieved that he (felt he) had been experimented on and that this experimental treatment had not been worth the reduction in quality of life.

At first contact in the day hospice Ernest had found a new lease of life through the use of computers. He had used 'Facebook' to organise a reunion of his former army mates and was a keen user of Skype. At the time of the interview his mobility was much impeded because of breathlessness and his painful hands. He could no longer type into his computer and he also could not operate his mobility scooter because he could not work the driving stick. He seemed very low in mood and was reliant on his wife pushing him in a big wheelchair. He bemoaned the steroid tummy and additional weight gain from the medication. He briefly talked of taking his own life should his wife predecease him. Outwardly and on first impression he was a jolly chap but underneath he was very sad and depressed.

The superordinate theme for Ernest was loss of independence informed by the subordinate themes which Ernest described:

- distress
- anger and blame
- grief for his former self
- coping

Ernest described the distress of diagnosis and symptom experience. He was keen to share the way his cancer was found. He had received treatment for a suspicious deep vein thrombosis which had led to a bone marrow biopsy. The procedure for biopsy using a large needle had been in itself traumatic for Ernest. The initial reaction of close relatives, to his diagnosis and prognosis, appeared to compound this experience and elevate his personal distress. His sister in law had 'broken down in tears' (line 24, 09). He described the isolation and anguish of having had 'nine months of chemotherapy' (line 27, 09). His perception of the experience was that he had been 'segregated' and

'locked up' whilst receiving treatment (line 32, 09). He also shared his reluctance to receive further treatment which he found debilitating:

'...(treatment) knocks me out, I'm laid out for a day after that.'

(line 250, 09)

His distress and lack of hope and resignation was expressed in stating 'this is never going to get better' (line 100, 09).

The experience of distress had developed into anger and this largely related to his treatment. Having endured the nine months of chemotherapy he was given 'bad news' (line 44, 09). The cancer had not diminished it had 'gone up...and exploded' (line 44, 09). The subsequent revised treatment had side effects of neuropathy for which he felt unprepared:

'...next thing I got a tingling in my feet'

(line 58, 09)

It was this altered sensation and distorted sensitivity to pain in his feet which he had found most troublesome. He was very angry about the second chemotherapy treatment '...I was very bad with that' (line 64, 09). He speculated that at one point he had been given the wrong treatment (line 66, 09). He felt that this had been unnecessary and related that one of his Doctors had confirmed this:

'I should never have had the...chemotherapy...I would have been all right. I wouldn't have had this problem I've got now.'

(line 71, 09)

Having neuropathy made him angry and caused him pain and discomfort. Ernest said:

'...my feet are terrible. I can't sleep.'

(line 77, 09)

He had had to adapt to the pain in his feet by wearing 'big slippers' and having a frame in his bed to take the weight of the bedding. His mobility was severely limited because of his foot problems:

'I can't walk anywhere. I can't do any exercise.'

(line 257, 09)

The only things which he could do, to make his feet more comfortable, were to use direct heat or the cold of a tiled floor. His favoured, if extreme strategy, was to use his chairlift to access the bath and put his feet in hot water:

'...soak them in water as red hot as you can get.'

(line 393, 09)

The down side of this was that at on at least one occasion he had burned himself in the excessive heat of the bath water. His hands were also affected by the neuropathy which left him mostly numb but often in pain (line 436, 09):

'I've got aches and pains in this arm...as if my muscles are going to burst out...'

(line 447, 09)

Other symptoms Ernest described included breathlessness and insomnia. Ernest also described feeling 'tired a lot' (254, 09). He perceived that he tablets he took for the neuropathy caused these other symptoms:

'side effects... because I'm on a lot of tablets.'

(line 84, 09)

He also accepted that 'it's never going to go away' (line 96, 09).

'I'm just what you call a wreck.'

(line 450, 09)

Ernest was annoyed because he had had so much treatment and he was:

'...having to suffer with other things in the meantime.'

(line 110, 09)

The loss of all his hair with the second treatment had been of minor concern to him. A major concern was that he had found that his mouth had 'started to swell' and he had developed mouth ulcers and 'ghastly things in my (his) mouth' (lines 151,152, 09). The pain in his mouth had made him unable to eat or drink, which he found very unpleasant. His teeth had also had to be removed because of becoming rotten and painful. The cancer was causing unnatural bone growth in his mouth which he pointed to. These cancerous bony protrusions were breaking through his gums and caused him a lot of distress (line 280, 09):

'...my mouth's my problem, its sore altogether.'

(line 290, 09)

The necessary management of his dehydration had led to increased frequency of urination and diarrhoea, both of which were difficult with his reduced mobility. He used personal metaphors to describe and make sense of the pain and his mouth problems. Ernest explained how the cancer had 'exploded' at various points and how the chemotherapy 'knocked him out'. He used the anger to describe the relationship which existed within his white cells which were:

'...fighting them because they don't want you to feed them...they go for your mouth...'

(line 163, 09)

This 'mess of a cellular battle field' seemed to make sense to Ernest (line 164, 09):

'You've got to persevere...and you get everything right back in your body.'

(line 166, 09)

Fighting and anger also related to the former self for which Ernest grieved:

'I was just cracking up and crying...because of the things I couldn't do.'

(line 188, 09)

Ernest had been a professional soldier having spent 24 years in the army and more recently had been a church warden, keen gardener and volunteer keeper of the local war graves. But now he said:

'I'm absolutely useless to everybody; I just sit in that chair.'

(line 420, 09)

He had been very active and had enjoyed a full social life through church and outings. This former life was one which he missed and through accessing a local forces charity he had regained some independence with the provision of a motor scooter. The same charitable organisation had given him training in how to use a computer and the internet through which he had managed to resurrect some of his army friendships via social media.

'I'm on Facebook...in touch with all my mates.'

(line 350, 09)

The improved mobility and enhanced communication skills helped somewhat 'but at the end of the day I'm still suffering' (line 216, 09).

'... I nearly had a nervous breakdown...'

(line 230, 09)

Coping with loss had become a big problem for Ernest. The extreme frustration with his reduced ability had caused Ernest to seek support from his local vicar. The church had provided him with the social network he needed when he left the army. His faith and the support from the Macmillan nurse were what he seemed to rely upon (line 234, 09). He had great faith in his GP (line 503, 09) to tell him honestly about any treatment or his prognosis but revered the hospital specialists' greater knowledge:

'If they cut my feet off... [I would] still have the tingling.'

(line 549, 09)

The hospice day centre also gave him comfort and reassurance where all professionals were sympathetic to his traumas. Outside of the healthcare setting he felt there was a stigma associated with having cancer which meant that he could not talk to all the people he wanted to. Despite presenting his faith and coping strategies, he presented mixed views on his current life initially firmly asserting the importance of his life and later acknowledging how much he depended on his wife as well as his faith:

'God's given me this life and I'm keeping it.'

(line 322, 09)

Life was difficult for Ernest, he was tough and had learned to cope, but he was clear that he could not live without his beloved wife:

'If my wife went before me I'm afraid it would be an overdose...'

(line 326, 09)

Participant 10 Bob

Bob introduced himself as a 68 year old 'rag and bone man'. He was proud of the fact that he had always worked for a living and that he still 'ran in' a little scrap metal for 'extra pennies'. Bob had been diagnosed with myeloma about 2 years before the interview. He was pleased to still be here and despite painful foot neuropathy he was

full of optimism. He was still part of a new drug trial and unconvinced that it would help him.

Bob alluded to his gypsy origins of which he was proud and which his wife disliked intensely. He had been to the Appleby horse fair and still liked to pick up bits of 'odd job' work. He detested shopping and loved the seaside. This was a tension between him and his wife as he suggested that he often had to go shopping for 'nothing in particular'. He seemed to continue despite his aches and pains with a very sunny disposition towards life and living with cancer.

The superordinate theme of the interview with Bob was independence. He focused on what he could do and how he could adapt. The subordinate themes which Bob shared related to:

- concerns about his painful hands and feet.
- dislike of analgesia
- dislike of the side effects of the treatments
- blaming old age

His initial diagnosis had been quite a shock for him as he described his tough and illness free life before the myeloma:

'I'm the last person in the world to go near a doctor.'

(line 65, 10)

He still worked for a couple of hours at a time 'to make a few quid' (line 358, 10) and needed his routine of working 'on a normal day' and chose to pace his working (line 143, 09). This animated, tough and independent self was the person he projected with references to his work and former pastimes. Bob was determined to keep independent through his existing activities. He was dismissive of his diagnosis, 'it is

fatal', and offered his prognosis of 'two months, two years, I don't know' to justify his *joie de vivre* (line 77, 10). He was a survivor and needed to tell people this:

'You are never going to be clear... but everything started to go away.'

(line 93, 10)

Bob's perception of his illness fluctuated from grasping at a cure to seemingly acknowledging that he would not recover. He had had to slow down:

'...because the body won't take it'

(line 133, 10)

However, his major responsibility was to his wife and he used his car to take her out most days. Bob also gardened but as with other things he had reduced the amount he did. One regret was that he would not be able to try new things and in particular might never go abroad because of the cost of insurance so this was 'not going to happen' line 400, 10). He was convinced that his state of mind was crucial to keeping pain and symptom free:

'Your attitude has got to be right or you're not going to win.'

(line 346, 10)

Despite his positive attitude, he found the neuropathy in his hands and feet, following chemotherapy, quite troubling. He could write with some difficulty and had had to 'train himself to write' with his non dominant hand (line 277, 10). He also tried to attribute this and problems with his memory to his age:

'...that's to do with age or being stupid or disease.'

(line 290, 10)

The pain Bob experienced in his feet was very severe, but not constant:

'I was in agony last week with them; I could have cut them off.'

(line 34, 10)

He described the unpredictable nature of the pain he experienced in metaphorical terms and was pragmatic in his descriptions of the pain:

'Last week it was boom... things come and go...'

(line 41, 10)

However, he gave a muted, if distressing, account of the painful experience of the bony overgrowth in his back:

'My bones were growing in my back...but less bend in it.'

(line 83, 10)

The pain in his hands was more worrying to him as his 'hand would lock' (line 251, 10) which meant he might drop things or worse not be able to drive. He could not help much with household chores because of his painful hands but this did not appear to distress him.

Bob had been prescribed a range of analgesics which he mostly did not take:

'I'll try and manage without...'

(line 313, 10)

The reason he gave for not taking his analgesia was because he had 'had enough tablets' and he would take them if he 'got a bad headache or (his) feet were really (bad)' (line 315, 10). He disliked the reliance on a routine of taking tablets.

Bob acknowledged the importance of having treatment for the cancer but he had reservations about the side effects. He reassured himself that:

'...when I've finished the course it'll (i.e. side effects) go away...'

(line 324, 10)

This optimism that he would feel better when he did not take the treatment gave him something to focus on and look forward to. He had volunteered for a new drug trial because:

'if it works it will give you a longer life.'

(line 96, 10)

He further justified his participation in the trial by saying he had 'to pay back something'. He did not want to be seen to have 'given in'. However, as the thalidomide treatment was one of the drugs which had caused the neuropathy in his hands and feet (line 85, 10) he justified his concerns that any new treatment might have similar side effects. Despite these worries he had participated in the trial and sadly his feet had become worse as a result (line 106, 10). He was mostly pragmatic about the pain and neuropathies implying that he might have had pain from getting older even if he had not had the cancer:

'...at my age I'd be getting things any way.'

(line 109, 10)

Bob turned these experiences into a positive account by saying:

'...at 70 you're bound to get bits and bobs...so...I'm winning'

(line 111, 10)

And later:

'There's no point in worrying ...just get on with it.'

(line 125, 10)

Participant 11 Hilda

Hilda had a thick eastern European accent. She had escaped from the Russian occupation of Eastern Europe over 50 years ago and had lost her first family; her husband and child were murdered by Russian soldiers. She had travelled alone with nothing and had taught herself English and 'worked for a living' never claiming any benefits and never visiting a doctor until after her 80th birthday.

Hilda was now 88 years old and a widow who lived alone, with one surviving adult daughter. Her pain, though she did not describe it as such was on swallowing and she found eating too painful. All her food had to be liquidised and she was reticent to say it caused her any difficulty except that she had lost a lot of weight and muscle mass. Observing her she would hold the base of her neck quite firmly when talking as if she was almost squeezing it.

The interview was largely a discussion of how Hilda did not have pain but if she did then her Christian faith and the 'Good Lord' would help her through. She believed that pain had a purpose to make you stronger. It was impossible to see beyond the 25 year old refugee who was evidently still in control of the 80 something old body even though full of cancer. The description Hilda made of herself, during the interview, was inconsistent with her body language and with what she said before and after recording commenced. She contradicted herself in some of the things which were observed by the researcher and in what was said during the interview and, when gently challenged about this, it was apparent that Hilda presented a 'self' which was outwardly very forbearing. The superordinate theme which Hilda projected was how her faith had supported her through this illness, she was tough and coped. The subordinate themes which were extracted included:

- Dislike of analgesia,
- Denial of 'pain' and cancer
- Loss of her former self

Hilda introduced the conversation by stating:

'...cancer don't worry me at all.'

(line 8, 11)

She used the words 'shocked' and 'very serious' to describe her reaction to being given her prognosis. To illustrate her toughness she repeatedly said that she 'was left to die' but had lived over three years since being told that she had 3-6 months to live (lines 29 & 84, 11). In fact, she had undergone a partial gastrectomy to remove the cancer and had lived for three years following this, despite refusing chemotherapy. She did not think she could cope with any further treatment and continued to pray that she would not have to receive any more treatment (line 92, 11). The doctor had been 'tough' with her and given her an 'ultimatum' to ensure that she complied with the surgery and treatment (line 95, 11). Hilda was consistent about her faith, she was very sure that soon after being given her diagnosis she had seen and spoken to Jesus, and because of this she put her 'trust in the Lord' (line 29, 11). Hilda's faith in God surpassed her faith in any medical person she was the 'iron lady' (line 48, 11). But, she acknowledged that she was also 'a very poorly woman' (line 67, 11).

Hilda said she rejected the morphine which she had been given, yet she had a bottle of morphine in her handbag as she was being interviewed. She related how initially, when a doctor had offered her morphine, she had most emphatically rejected any analgesia:

'I said Doctor; I don't want to take it. I don't.'

(line 33, 11)

Later in the interview she pointed to the bottle in her bag and said that the morphine had:

'...run out of date, but...they're sending a new one.'

(line 123, 11)

She described an incident of an apparent heavenly vision, perhaps a hallucination, of which she had detailed recollection, whilst in hospital. This episode had resulted in some of her pain medication being stopped and she described how she believed that her insistence on discussing this with multiple doctors had damaged her relationship with at least one of them (lines 226, 232, 11). She relied heavily on her GP and revealed some tension with her daughter about what she should be told:

‘I can yes, I can decide for myself, so they’re supposed to talk to me first, not to my daughter. ‘But my daughter is pushing herself, she wants to know everything, she thinks she’s the patient, but she got to know...’

(line 247, 11)

Hilda had acknowledged the pain in her stomach at the beginning of the interview, despite having stomach cancer (line 30, 11). Later in the interview any references she made to the word ‘pain’ were rebuttals of having any pain. Hilda said she did not have any pain in her stomach but described considerable discomfort in her chest and how this affected her breathing (line 46, 11). She stated several times she thought she no longer had the cancer (line 184, 11).

Another contradiction was related to her description of her ability to eat normally. When Hilda was describing her diet she said she had ‘a good appetite and could eat practically everything’ despite recently having been observed eating a homogenised plate of food and describing the pain she experienced on swallowing (line 60, 11). Hilda did acknowledge, on tape, that she had to eat slowly and the food ‘got stuck’ at times (line 134, 11). However, she preferred to blame this problem on the amount of chillies she used to consume (line 144, 11).

The complaint Hilda most wished to share, in the taped interview, was the tiredness and fatigue she experienced (line 61, 11). Hilda was very quick to respond to questions about her pain in the interview with ‘no pain at all’ (line 76, 11). However, Hilda sat through the interview clutching and rubbing at her lower neck and chest.

Hilda grieved for her former self and she described how she had been very fit and active until the cancer. She had lost 3 stones³⁶ in weight initially and had recently lost another stone. Hilda described how she no longer liked to look at her body.

'I used to have lovely arms...I'm bone and skin now.'

(line 159, 11)

She had given up swimming because she was embarrassed about how emaciated she looked. She had also enjoyed walking but found that she was no longer able to do this because she was feeling dizzy and experiencing so much fatigue (line 183, 11).

5.3 Summary

The vignettes here represent a small group of older people with cancer pain. All the participants interviewed had unique experiences and accounts of themselves. They willingly shared much of their lives and some of their fears but all shared their important roles as part of families and communities which they presented as part of their unique identities. Analysis of these interviews highlights the way that having a diagnosis of cancer and its consequent physical, psychological and social effects has affected each person. It is important to appreciate that even those individuals with similar diagnoses and prognoses had different experiences. These interviews can only represent a snapshot of the individual experience. Similarly the two week diaries, where completed, could not be considered as truly representative of the lives of each of the participants. It is also important to note that alongside these divergent perspectives of living with cancer pain there were some convergent areas or major themes and that these will be explored in the next chapter.

³⁶ One stone (14lbs)=6.35 kg

Chapter 6

Findings 2- Interpretative Analysis

6.1 Introduction

The preceding chapter illustrated the descriptive and nuanced accounts of individual participants which involved a first level of interpretation. This chapter continues the iterative process of analysis and builds on and extends the superordinate and subordinate themes identified in chapter 5 to generate master themes which reflect the experiences of all participants as a group. This chapter presents i) the overarching master themes between participants and across cases, ii) their relationship to and development from the individual transcripts and iii) the individual subordinate and superordinate themes which were common to most participants. The importance of reflexivity, within the data collection and the interpretative process, is also considered. Layers of complexity and interpretation have led the researcher to revisit the original data from which the themes are derived. It is through this repeated process of reading and rereading the transcripts in conjunction with the existing individual themes which has led to the development of the master themes as represented in Figure 9.

6.1.1 Note on reflexivity

The reflexive role of the researcher, in the interpretation of the data and the construction of these themes, has been acknowledged in order to appreciate the effect that the researcher may or may not have on the subject under investigation. Reflexivity is also the process of considering oneself in the role of researcher and considering the relationship with the people who are subjects of the research. Reflexivity starts with the epistemological (assumptions about the world and our knowledge of it) position of the researcher, plus any stereotypical assumptions about the topic and the participants (Mauthner & Doucet 2003, Kinsella & Whiteford 2009). Reflexivity must also include a critical awareness of the quality and limitations of the

research methodology. Reflexivity in qualitative research can be used to gain greater insight into the way researchers and practitioners interact with their clients (Willig 2008). Since the process of interview is interactive the thoughts and notes of the researcher, both contemporaneously and post interview, are regarded as important data to be considered and acknowledged as both informative and influential on the descriptive and interpretative process of analysis. Moreover, the emotive nature of some of the personal accounts within this study meant that objective detachment was neither ethical nor realistically achievable. Thus, the identified themes emerge from both the interview and diary data and inevitably are informed by the researcher's prior knowledge, and understanding, of the subject under discussion i.e. health care, pain and cancer.

6.2 Interpretative analysis, introducing the themes

Five overarching themes, which exemplified the common areas of concern, were extracted from the available data. These themes were:

- Better to be old than to be dying with cancer

- Maintaining control and independence

- Loss of identity- adapting and grieving for a former self

- Dislike of analgesia

- Denial of pain

These major themes represent development, a second level of interpretation, resulting from the iterative and cyclical process of revisiting the superordinate themes, sub themes, themes and the original transcripts, thus reflecting the original data from which they are derived (Willig 2008). This second level of interpretation is tentative

and thus more speculative (Larkin *et al* 2006); these master themes propose a perspective on how the participants collectively experienced cancer pain and the important topics which emerged from the data. Though major themes and commonalities were noted, it is important that in this chapter the idiosyncratic and subtle content and context are respected. Even within a purposive group such as this, where all participants are older people with cancer and pain, the participants were by no means homogeneous. Hence out of respect for the individual, examples of the original data, from which the master themes are generated, are included in the sections below.

Appendices C-F summarise the development of overarching themes across cases from the individual superordinate and subordinate themes. Whilst most major themes were consistent in all interviews a small number were common to a smaller sub group of participants, this is detailed in this chapter and summarised in the table in Appendix C.

The order, in which these themes are presented, broadly reflects the points at which they occurred in the interview, in part because of the structure of the interview schedule. However, this does not necessarily reflect a hierarchy of importance to the participant, nor does it reflect the frequency of occurrence in the transcript.

6.2.1 Better to be old than to be dying with cancer

Despite having very different experiences, a significant and important finding of this study was the way the participants presented themselves as people who were old rather than as people with cancer, which was surprising given the age range (67-88 years). The subtext to this was that the majority of the participants blamed being old or the cancer treatment for the majority of their health problems. In this regard, Ethel and Robert are noteworthy because of their apparent unwillingness to focus on cancer as the cause of their pain and current health problems. It was apparent that having something other than the cancer to focus on appeared to be preferable to acknowledging cancer as the cause of their symptoms and physical limitations.

This might be considered superficially as a theme about stoicism. Indeed, early comparison of the transcripts suggested that stoicism was common to all participants. Initially this theme appeared to fit with the 'older stoic' generalisation; however, this over simplifies what is clearly a very complex, multi-layered issue. After repeated reading and listening to the recordings it became apparent that this was one of the 'faces' that some of the participants chose to present.

All participants variously blamed their chronological age for some of the distressing symptoms they experienced. It is a reasonable premise that the co-morbidities of ageing might account for some of the pain. Being old was easily used to rationalise some of the pain and problems, particularly for those who reflect a positive disposition towards life and the trauma of cancer. Ethel was an example in this regard.

Ethel was apparently convinced that all the decorating she had done as a young woman and all the other physical activities were somehow responsible for all her aches and pains:

' I've not got arthritis as I know to but maybe I have in my legs and that but you see I used to do a lot of (things) for people, I used to do a lot of papering, decorating. And I think going up and down steps I

am paying for that now. So I don't know whether it's all down to my illness or... I don't think it is, I think it's a mixture...'

(line 101, 01)

Here Ethel reflects the experiences of a number of the participants in describing the 'wear and tear' of having lived a long full life. The experiences of the participants varied, in that they described different activities and roles. In connecting the symptom, or reduced function, to age and co-morbidities of ageing reflected a common coping strategy for dealing with a negative experience.

For each of the participants there were at least two identities: the older person and the person with a terminal cancer diagnosis. Presenting an identity of being old was preferable to being identified with terminal cancer, with an associated ambivalence towards the prognosis, as exemplified by John:

'My body's telling me stop, and I did. I'd always listen to my body, what it tells me...'

(line 122, 05)

There were repeated references to the body wearing out, almost to imply the certainty of pain with age rather than choosing to associate it with the cancer. Fred gave a succinct example of this:

'I mean at the moment, when I'm sitting here, I've got pain just across the top of my pelvis now. As I say, the body is just getting worn out'.

(line 636, 07)

Pain could easily be attributed to other causes related to ageing. Fred made a clear distinction between his age related problems and the pain attributable to cancer. Perhaps Fred found this was easier to cope with:

'...as I've been saying to you, I mean these pains as far as I'm concerned they don't seem to be relevant to my cancer.'

(line 798, 07)

Ethel, who was in quite a lot of discomfort at the time of interview, was quick to say that she had a 'broken back' (line 26, 01). She was clear that in the 18 months since she had started treatment, rather than the growth of the cancer, there must have been another contributory factor in her worsening back pain:

'I've been on it (treatment) for two 9 months and last time it was harder than the first one but then again I was going on for 18 months older than what I was before so that must make a difference'

(line 35, 01)

Three of the men Robert, Ernest and Bob notably blamed their cancer treatment additionally for their distress and with some justification. Robert had issues with his cancer treatment but also shared that his other diagnosis of diabetes might be a contributory factor in his experience of pain:

'I have a thing called diabetic neuropathy, which affects your nerve ends and things. So I have problem with my feet and also my finger endings. Especially my left hand, fortunately I am right handed. My left hand, these two fingers, they're constantly numb so I can't hold anything hot in this hand.'

(line 48, 04)

Robert blamed some of his medication and the creation of an arteriovenous fistula, for his renal dialysis, for some of his circulatory problems:

'The artery collapsed and there was no circulation to this left arm, no pulse at all, so I thought it might have had a big effect on these (fingers)...

(line 54, 04)

For a man who lived to do DIY this seemed a particular impediment to activity, Robert had worse to say of his medication:

'They, er... the side effects of the tablets were not helping...and it is because of the c**p in those tablets, of course the kidney failure. And of course year after year, the rottenness of the tablets...'

(line 66, 04)

Robert was particularly scathing about the side effects of treatment on his appetite:

'It's like the tablets I have prescribed for my shoulder. They're ok because they take away the pain and everything and helped with my neck, to exercise my arm and to get my shoulder back to normal. But, the side effects of those tablets are absolutely horrendous. They make you feel quite sick most of the time, I couldn't keep my grub down, I lost my appetite and was generally feeling rough as a ...'

(line 72, 04)

Not all responses were the same in relation to the similar treatment options as exemplified in the accounts of Ernest and Bob who described almost identical treatment plans. Ernest and Bob both had been diagnosed with myeloma, both had received high dose chemotherapy and plasmapheresis to reduce blood viscosity followed with thalidomide to manage the bony overgrowth.

Ernest had much to say about the damaging and debilitating experiences of chemotherapy and the drug thalidomide. Ernest expressed that he had not been adequately informed of the side effects of his chemotherapy and of the way the cancer could affect him, particularly in terms of bone and mouth pain. Ernest also felt strongly that his treatment had not been properly managed as per this account:

' (Doctor X) she said it's the chemotherapy that's causing it, stop it straightaway and tell the people at ..(X clinic)... to stop it. And that

was twice a week I was having it, on a Monday and a Thursday, and I was very bad with that. And then they stopped it and said we'll get you into the hospital. But the problem was in between I should never have had the chemotherapy, they kept me six weeks instead of three weeks to go in. Now that was a problem with the (X hospital) having no accommodation for me, and (Y hospital), I don't know what happened there. Anyway I should never have had the ... chemotherapy, I should have gone straight in ... and I would have been all right. I wouldn't have had this problem I've got now. But now I've got neuropathy and you can see I've got to wear special slippers and shoes and everything. (line 61, 09)

This description reflects a combination of positive and negative features of having treatment and is an example of the need to find something or someone to blame. Ernest had also lost confidence in the treatment regimen and reflected this in his description of the apparent disorganisation of the planning for his treatment. Also, the tablets Ernest took for his pain and to manage his other problems caused him problems. This explained his reluctance to take the analgesia:

'Other side effects; out of breath, sleepless, I can't sleep at nights at all because I'm on a lot of tablets, Pregabalin, Oxycodone, all sorts of tablets to relieve the pain from my feet and my neuropathy.'

(line 84, 09)

Ernest's description implies that these analgesics could be effective. It is however, the negative features which are focused on, the associated breathlessness and insomnia. Bob similarly recounted that his neuropathy was caused by his treatment but he appeared to have been better prepared for this as noted in this account:

'...in the treatment, there's thalidomide to stop your bones growing. Because my bones were growing in my back and they were, well a few are coming back now but less bend in it. And that is, the

thalidomide is to stop your bones growing, but it kills the nerves in your feet.'

(line 82, 10)

In contrast to Ernest's account, Bob did generally seem to have a more positive and pragmatic view of his treatment options as exemplified by his response to being offered the chance to participate in a new cancer drug trial:

'When they got to the end of my treatment and we got like a three month period of freedom if you like, where you've got better and you're on the move and I went back to, oh yeah you're clear! Well you're never going to be clear clear, but you're in remission, you're fine, and everything started to go away. I started to put weight back on and top of world. And then they said would you like to go on this trial? I said well why? Well if it works it'll give you a longer life. I thought well I'm all for that. Plus they've done that much for me I thought yeah I've got to pay back something, you can't just walk out and say, you know. She said we've got three options: you can go on this trial, do it at home, or you can come here twice a week, or you can just walk away and come back here when it comes back. I said oh, no that's giving in, I said no, no...'

(line 90, 10)

In this extract treatment is not always considered effective but a positive experience is acknowledged in the hope and expectations which this can provide. Bob seemed almost to be reconciled to the probability that the hope of a longer remission might be dashed in this extract:

'So I went on this trial, but everything come back again in a smaller way, and they said it would, the side effects would be the same as you had before but not so severe, and my feet's been worse thing really. But it comes and goes, I don't worry about it. And that's

another thing, if you worry it gets worse. So why worry about things, just get on with it. You have good days and bad days ... so to look at it in a proper way I'm winning. You know, I didn't lose all my hair, I lost some of it, it's come back.'

(line 104, 10)

Despite his poor prognosis, the concept of 'winning' reflects both Bob's positive disposition and the need to focus on anything that is vaguely positive. The mixed feelings which Bob expressed towards his symptoms clearly reveal some reservations but, on the whole he is positive. Bob clutched at the positive experience of having thicker hair when it grew back and that things were 'not that much worse'.

Bob was also quite clear that his age was a significant factor in explaining why the treatment was less effective:

'Well yeah, I've slowed down a lot, I've had to slow down because the body won't take it. It wouldn't take it anyway, not at my age. You think it will, your mind says get on but your body won't take it, so I've had to cut my cloth a little bit and I'm not happy about it.'

(line 133, 10)

This ambivalence of the participants, towards their varying treatment options, reflects the mixture of positive, negative and sometimes contradictory experiences encountered by the participants at various times in their treatment journeys.

The idea that the cancer was not primarily to blame for any pain or other distressing symptom was expressed in different forms by each of the participants. The strong implication from the participants was that this was a diversionary tactic, a way of managing or ameliorating the distress of fully engaging with the symptoms and their causes. One reason for this apparent lack of full engagement with their diagnosis and prognosis was implied by Ernest that of stigma and blame:

'Some people have got a stigma if they've got cancer, a big stigma about it...'

(line 237, 09)

Ernest was suggesting here that having cancer might not evoke sympathy or even support from others because of perhaps being a contributor by some lifestyle choice, such as smoking, for having different kinds of cancer:

'I've got a lot of feelings about....you've got to have it first to know what cancer is and what it's about'

(line 234, 09)

The feelings and emotions expressed in the interviews generally conveyed a sense of needing to be in control of a desperate situation where age was expected but cancer and its debilitating consequences were not. Whether consciously or otherwise, the participants in this study were trying to convey a message that their cancer's status was not as significant or problematic as others might imply rather they preferred to be thought of as people whose bodies were old and largely worn out and they needed to attribute blame to something they understood such as being old and the cancer treatments.

6.2.2 Maintaining control and independence

All nine participants identified the importance of maintaining control of their lives to keep their independent status (see Appendix C). The participants described how they coped, in terms of maintaining their physical function or daily activities, to facilitate their independence. Being in control and managing their daily lives were essential for maintaining independence. The impact of having been diagnosed with cancer and the subsequent treatment had meant that all participants had experienced significant changes to their lifestyle and daily routines, and they described how their expectations and ambitions had been modified. Positive responses to requests for help and support to maintain independence were, for the most part, welcomed. Descriptions of living were rooted in the present and no long term strategies were described by any of the

participants. The future was not discussed much by any of the participants; all had very short term goals. However, the most commonly shared goal seemed to be to maintain independence.

The participants in this study who lived alone were Ethel, Robert, John, Fred, Dougie and Hilda. They seemed to particularly value the control they had over their independence and expressed pride in the way they managed with minimal support, from family members specifically. They expressed their ability to be self-sufficient with a variety of mundane daily activities and chores. These older people did not wish to put demands on their family members or to be perceived as a burden on others.

A pragmatic approach, to life and the activities of living, appeared to be an essential component of being able to live independently for all. Fear of dependence was the contradictory narrative in the interviews, in describing their lived experiences they were holding onto 'self' and overtly resisting threats to its integrity. A strange mix of pragmatism and fear towards pain and losing independence was presented. The account of Robert is an example of this. He did not like having the pain, or being forced to resort to taking analgesia because he knew it would disable him for hours or more. But, he had prepared his home with various gadgets and supplies just in case he became confined with the pain:

'I've always got plenty of juice and stuff in. I just wake up andfill them (bottles) up and stick them at the side of (the bed)...

(line 308, 04)

Ernest similarly had a complex relationship with pain and managing his independence:

'...and that knocks me out...I've got a lot of puzzle books in my bedroom... I've got an exercise bike what I bought with rowing things on it...'

(line 249, 09)

Ernest was keen to show that despite his pain and neuropathy he used distraction techniques as well as analgesia which had some benefit in partially supporting his mental and physical ability. In particular, the computer had given him enormous enjoyment and enabled him to reconnect with many family members and former army friends:

‘Oh it’s absolutely changed my life that... shopping online this week, I said no we’ll go, no let’s do it online for a change.’

(line 375, 09)

Ethel also used distraction to help her manage the pain and had incorporated this into her daily routine.

‘I do a bit of knitting. I do a lot of crosswords, I love crosswords, I love all those competitions, soduko and all that sort of thing and I er I knit a bit for my little granddaughter for er, if she needs anything. I’m going to knit her a cardigan. She starts at school on an afternoon in September, so I’m going to knit her a cardigan to go to that. But, other than that I just ... I like to read a bit and er the crosswords and all competitions they are my main.... I love to do things like that’

(line 332, 01)

Constructing and presenting an apparently pain free or minimalised pain experience was apparently intended to reduce the risk of losing independence, as illustrated in Ethel and Hilda’s accounts. Ethel’s independence was linked to her role as supporting mother and grandmother. She needed to be resourceful and manage her pain experience to live independently. Hilda’s unwillingness to express her pain was possibly linked to her fear of dependence, and fear of dependence on her daughter was a major motivating factor and central to her making or allowing changes to enable independent living.

Accounts of the experiences of coping or adapting were common to all participants. For most the simple expectation that they would continue to stay in their own home was a major concern. Eric's detailed account of the disruption and expense of adaptations made to his own home depicts this very strongly. The experience of having limited physical capacity, fatigue and other debilitating problems caused either by the cancer or the treatment had led to profound and personal responses from each of the participants. Individuals who described where their expectations of their own ability were not met were either distressed and unhappy or dismissive. This was reflected in the varied accounts of enabling and inhibiting factors as perceived and described by each of the older people. This divergence of experience between participants of striving for independence is exemplified in the starkly contrasting accounts of participants Ethel (01), Dougie (08) and Ernest (09). Ethel was mostly accepting of her illness and reconciled to her limited ability through her accounts of adapting, reflecting some degree of perceived control. In contrast, Ernest was mostly upset and angry about how his life had changed and he apparently had lost control.

'Anyway I should never have had the ... chemotherapy ... and I would have been all right. I wouldn't have had this problem I've got now'

(line 69, 09)

Relating both her acceptance of the prognosis and her now limited ability Ethel described her attitude and outlook on life and independence. She made direct reference to neighbours and others who were in worse circumstances than her. The potential for being more dependent or becoming 'a burden' on others was directly or indirectly referenced by all. Ethel did not want to become dependent, and keen to show she was still relatively independent, about one particular neighbour Ethel stated:

'I can do for myself, (she) needs virtually everything doing for her'

(line 365, 01)

Ethel was emphatic that she needed to accept her cancer, as a part of the normal scheme of things. The alternative was just too unacceptable for her to consider.

Well, all right. You just have to... you just accept these things. You can't let it get to you or life would not be worth living.... would it?

(line 46, 01)

To endorse this perspective, of maintaining a normal routine to cope with her cancer diagnosis and prognosis, Ethel gave detailed accounts of how she had modified her activities to manage the daily chores. She described how she managed her laundry without having to do much painful standing:

'To get in I pull a chair forward and sit on the chair. I manage to get in, in that way. You just...it compels me to be that little bit more independent. Somebody would do it for me but I like to you know you just... it makes me feel better to do it for myself.'

(line 153, 01)

Ethel could be regarded as just being stoic here, but in acknowledging some frustration; she implied that this might just be a pragmatic view:

'And er I used to take my nephew's kiddies out and I feel I've took them out and took them all over the place and now I can't take my own you know it does get to you a bit. But, then it's just one of them things I can't help.'

(line 205, 01)

The way of phrasing the words she used to describe her experiences might be considered representative of her expectations as informed by her working and general life experiences, showing a life time's developed resilience. For example holidays were once enjoyed but are not possible now and not really necessary as implied by this quote from Ethel:

'I liked my holidays when my husband was alive and that but...He had Parkinson's disease for about 18 years and er he we were members of the Parkinson's society at Rotherham and we used to go on trips and holidays and allsorts with them you know so I said... I'm not bothered now I'm quite happy to stay at home.

(line 305, 01)

Ethel described her former life by referring to this example of holidays. In this quote, she appears to deflect the significance of what she cannot do by suggesting that holidays are no longer important to her. This stoicism might be a well practised way of representing herself to health professionals. Ethel is also dismissing the things she cannot do anymore because she does not wish to identify herself as vulnerable and no longer capable of doing things. Admitting that she is no longer able to do things might make her upset or worse compromise her independence and her social life leading to possible isolation and loneliness. The worst consequence for Ethel was the prospect of not having visitors or being there as support for her daughter and grandchildren:

'Well you have to do, don't you. I mean I've got summer holidays coming up and my daughter, her partner's left her and she is on her own with two children and of course they are off school aren't they...'

(line 290, 01)

This reflected Ethel's need to hold on to her role as mother and grandmother in supporting her children with their needs. Other references to her family responsibilities suggest that 'being there' for her family and friends were major motivators to be independent in her own home. Ethel also took pride in her ability to adapt and do 'normal' housekeeping activities albeit a lot slower and more painfully than before (line 42, 01).

Dougie was equally pragmatic about his prognosis and the way the cancer affected his life:

'...my mother always told me never to bother about anything you can't do anything about, and that's it, I've been like that all my life'

(line 174, 08)

Dougie was apparently happy with his life past and present, continually seeking new ways to maintain his physical and social independence:

'It's been a full life... Well I'm doing computer classes at the moment, so I can keep in touch with my friends abroad in dogs.'

(line 264, 08)

Ernest in contrast found it very difficult to deal with the changes he had experienced:

'And now I got down and very low and I was having, I was just cracking up and crying and crying and crying, because of the things I couldn't do.'

(line 188, 09)

Ernest had found his diagnosis and subsequent treatment a profoundly dreadful experience and he found little to be cheery about. He was particularly distressed at not being able to get into his garden or do his volunteer work at the church and cemetery. Ernest felt cheated of the life he had once lived:

'I'm 72 years of age coming up in August, born in 1942, and I should still be digging the garden, well cutting the grass and seeing to the garden, cutting the edges, doing the war graves still. That's what cracked me up.'

(line 223, 09)

Fatigue and pain were equally significant and problematic for Ernest, he had put on a lot of weight because of the treatment and his limited walking ability and the added weight made it more difficult for him which compounded his distress:

'...I can't lose weight either because I can't walk anywhere. I can't do any exercise. I've got an exercise bike what I bought with rowing things on it, and 10 minutes on there and I've had it, I'm out of breath and everything. So that's out of the question.'

(line 257, 09)

Ernest was still clearly grieving for his former self and his loss of ability to do the things he considered important. He was distressed at not fulfilling his role as husband, not only in regard to the household but personally, and he sandwiched in between sad jokes, a brief reference to being impotent because of the neuropathy (line 456, 09) and quickly moved the conversation to another topic. He conflated his own grief at this loss of function with the death of many of his soldier colleagues. He was struggling to cope with his loss of ability. However, Ernest found some joy in regaining some of his independence by having a motor scooter:

'An electric chair, a big one, state of the art one for the road, with mirrors and blinkers and everything, and even a tax disc on it. So I can go on the road with that wearing a luminous jacket, so I can get round the village. I've got my life back, more freedom, and I can get out on it.'

(line 209, 09)

Mobility was a major issue for Eric (06) as well. Focusing on mobility, rather than what he could not do, Eric had a very different response to his cancer. Eric had loved driving and was primarily concerned with keeping mobile. Because of his partial paralysis, Eric delighted in all the ways his home and living environment had been modified to ensure his maximum independence and to minimise the burden on his wife.

Eric had little lower body strength but had worked hard to adapt:

'... I can stand but no real (strength), can't really turn. I might be able to turn but I'd be using my arms. You know, lifting, I've got a bit stronger up the arms area to compensate for them. So I could probably turn from the chair onto the bed, but I'd be using my arms I think...'

(line 89, 06)

Similarly, Fred had been very independent and he was finding his increasing pain and fatigue a problem. He recounted a recent trip to the seaside where he had expected to manage quite well:

'...and I remember we walked down to the beach, it was about 100 yards, and I was absolutely whacked. When we got there, I had to find a seat and sit down for about half-an-hour before I summoned up the energy to walk back.'

(line 21, 07)

In contrast, domestic incapacity had not been a problem for Fred before his diagnosis, his wife had done everything at home, and he was in no hurry to learn how to manage any household chores whilst he had family and friends who would do things for him (line 291, 07).

Independence was compromised for Ernest and Hilda because of the physical changes which made them feel less attractive or even abhorrent to others. Ernest was distressed at his loss of teeth and the new cancerous protrusions in his mouth which meant he was self-conscious and embarrassed to talk to people. He was embarrassed at his changed self and thus reluctant to socialise.

Hilda presented herself as a 'tough' independent lady and she had many things that she could no longer do but the one thing she missed most was feeling able to go swimming. She clearly mourned for her former independence; intertwined with this

was the dislike for her current physical self and thought others would find her repulsive (line 163, 11). Additionally, Hilda could no longer walk very far so by ceasing to go swimming she had stopped doing any form of exercise.

Despite the accounts of fears related to independence all the participants greatly valued the social opportunity that the day hospice afforded. Being in the company of others with similar experiences not only appeared to give comfort but aided their sense of independence through socialising, as summed up by Ethel:

‘Well yes I’ve made some good friends and er of course the nurses and staff. Everybody’s so good to you and of course you have a nice meal and it’s a lovely day’.

(line132, 01)

The wider view of independence also related to fear of isolation and loneliness, tempered with the need to have freedom to manage daily living. Independence, in terms of being in control over care and the future, was barely mentioned but clearly important and hinted at in most of the conversations except by Hilda. Hilda was very concerned about being in control over her own life and she was emphatic that decisions should not be made about her (line 255, 11).

Robert was unique in the way he used of food and food preparation metaphors as examples of coping and staying independent. When asked about his independence Robert made frequent references to food preparation as an indication of his ability to look after himself:

‘Yes, erm yes I erm ate something...(long pause) roast chicken with an onion and mustard gravy. With some roast potatoes out from the freezer. It’s quite easy really just take it out of the freezer, read the instructions pop it in the microwave and then it pings and then it’s done for a minute and the meal is all there ready and cooked.’

(line 442, 04)

Each individual account noted unique ways in which the older people adapted to living with cancer. In these accounts they noted responses which varied from shock and denial through to acceptance in the adjustments they had made to living with cancer and pain. They all talked a lot about their mundane and everyday activities such as shopping, preparing food, eating, washing and getting out of the house to socialise. In these descriptions, there was some comparison made with contemporaries, who were considered less able or more disadvantaged, to present themselves as better off and less ill. Activities were mostly described in terms which suggested stoic adaptation or acceptance of reduced abilities but which were comparable to those of similar ages. These comparisons enabled them to regard changes and difficulties experienced as nearly normal and less important overall. Thus, what the older people could or could not do was clearly very important to understanding their lived experience.

6.2.3 Loss of identity- grieving for a former self.

One of the dominant issues, which related to all participants, was how they conveyed their identity, sense of self and adaptability. Identity was adapted and reaffirmed through narrative descriptions of current and former selves, roles and places. All the participants in this study identified themselves through their social encounters, their relationships and their former selves. Almost all of the participants gave detailed accounts of how they had lived with and continued to adapt to their symptom experience. All the participants described themselves in terms of their capacity and adaptability to maintain self.

The accounts of the participants' previous roles and experiences often dominated the conversation, clearly because they wanted to be seen as people who had lived full and varied lives. In describing their lives as lived before the cancer, most participants were showing through these biographical accounts what they had lost and what they needed to keep of their former selves. Thus, identity was endorsed by biographical account to display their unique and personal self.

The interviews were purposefully unstructured to allow freedom of narrative and maximise the potential to enter the life world of each of the participants; which

encouraged accounts of striving to maintain roles and identity in the midst of a major disruption in the form of a cancer diagnosis. As a direct consequence, a significant part of each conversation was about the biographies, the rich identities of these long lives. For each participant, it was an unspoken requirement to focus on the person before discussion of the illness. To listen to what they gave as their account of living with cancer and pain and to appreciate this in the context of their lived experiences the interviewer was directed to understand who they were, what they had done and what they had been to others.

Of all the biographical accounts Hilda's was the most dramatic. She had had a difficult life in which she demonstrated considerable tenacity and resilience. Perhaps, in this unique case she perceived the experience of living with cancer as less distressing than the ordeal of her war experiences, which included the loss of her husband and child. It is difficult to know how the psychological traumas of her early life may have affected the responses she gave. Her tenacity was still evident in her depiction of a very independent life; but, sadly she could now describe herself as weak and as 'a very poorly woman' (line 67, 11) and contrasted this with her strong desire to maintain some quality of life.

'I went down ever such a lot. But I'm still all right, so... but I just
(keep going)...

(line 166, 11)

The army had been an important factor in the lives of most of the men because of National Service³⁷, and two, Fred and Ernest, had been career soldiers. This projected a unifying force, implied stamina, strength and toughness in their personalities. Fred personified this stereotype; he had been a runner and especially fit whilst also in the army:

'I was a runner at one time. Well I used to do track in the summer
and cross country in the winter. The kind of thing I'd be running is

³⁷ Men in this generation a minimum of two years of compulsory service in one of the armed forces with few exceptions.

anything from the half mile to three mile, would be about six miles, and then for training I just used to run on the roads. When I'd finished work, before I had my dinner, I'd go out and probably run about four or five miles to have a bit of training. That was the kind of thing, just training. I mean it's like I'd run down to the running track, which was about three miles, and then I'd probably do about 24 quarter mile sprints'.

(line 175, 07)

In this excerpt Fred clearly wanted to identify and contrast his current self with the energy and stamina of years past.

Ernest similarly used examples and metaphor from his army career to illustrate his preferred attitude towards the cancer and the cancer pain:

'...right, well can you remember what Winston Churchill said, we shall never surrender.'

(line 460, 09)

Ernest mourned for his former self and he was proud of his lengthy army career:

'I joined the army in 58 as a boy soldier; I'd had a bad life with a step father who knocked us about. At 16 I said to my mother take me to Doncaster please, and we'll see about getting in the army, and I signed on in the East Lancashire Regiment and went to Formby just outside Liverpool first, and then to barracks at Preston, Lancastrian Brigade. And I was a junior drummer, and then a drum sergeant, and then I went into the police in the regiment looking after the guard room and naughty boys. And then I decided after 24 years I'd had enough, I'd done my 22 and two years boy service and came out. I had a great career.'

(line 341, 09)

In identifying himself as a former soldier, Ernest wanted to parade, through this account, the tough and hardy person he had been and still wanted to be:

'24 years in the army, in the Queen's Lancashire Regiment. And I didn't know what to do with myself.'

(line 191, 09)

Fred similarly had a strong identity through his army career and wanted it known:

When I was in the Air Force, I was in charge of discipline...'

(line 406, 07)

John used the same soldierly language to identify himself as a miner and much of his language was peppered with metaphor or direct reference to 'fighting'.

'I fight it like in a positive way you're like talking to yourself in your head, get away, get off and all this. It seems to work'

(line 222, 05)

John carried this use of war metaphor into his descriptions of dealing with the cancer. Alongside this tough persona, John was aggrieved at his current dependency on others and his limited mobility. He recounted tales of the former self which he had lost. In particular it was through his identity as a miner that he related much of his life and his losses. John was sad at the loss of past years, the loss of work as a miner, the passing of his children's childhood, his widowhood, the loss of one of his children and a grandchild, and the loss of control over his future following his cancer diagnosis. Though all these losses were mentioned, he did not dwell on any of these in particular; instead he focused in detail on the more recent loss of his beloved greenhouse which had been sold:

'... I had a big greenhouse on it, see I didn't know what was happening, if I was going back there, and silly thing I've done. My lad come and said there's somebody would like to buy your greenhouse dad and all that, and me thinking that I'm going to be here all the time... And now I'm wishing I hadn't.'

(line 189, 05)

The manifestation of John's grief towards his greenhouse appeared to represent the grief of his greater losses but in a more acceptable and palatable form.

The importance of professionalism was pivotal to appreciating some of the other men's identities. Dougie and his wife had been international dog show judges (line 185, 08). In stating this Dougie also wanted to present himself as a person of importance and standing in the community. He was immensely proud of the dogs they had bred together and in particular having achieved best of breed at Crufts (line 244, 08).

Robert had been an aeronautical engineer and had clearly loved his former life and home. Though retired, he had lost much including family through having cancer and his subsequent relocation to be near his caring sisters. He had lost his community standing and professional identity. His account of living in a tiny bungalow reflected this loss:

'...moving into this smaller place erm... a lot of my amenities I had to get rid of... My second bedroom now it's got my tumble dryer and freezer in there because there was nowhere else in the kitchen to put it. There's only room for a washing machine and small fridge and that's it.'

(line 372, 04)

There was a great deal of pride in all these accounts of lives and living before old age and before the cancer.

Eric's loss of identity was evident in his account of being unable to access the same services and mobility allowances which those aged under 65 years could access. He

had legitimate grievances about the inequality of services and resources which were and are restricted to those under 65. As someone whose job and social life had mostly been related to driving to places this caused him both anger and distress. The anger about this lack of resources seemed to capture the anger he felt about his cancer and mobility issues and had given him a focus for the associated negative energy. The independently mobile former self was what Eric missed most. His golf, his holidays and social life had diminished:

‘...and motor home which we did together, we loved that didn’t we, both of us. I mean it’s absolutely sickening isn’t it in a way, not being able to use that.’

(line 664, 06)

Bob had lost his identity as the ‘bread winner’ because he was self employed and not retired at diagnosis and he had enjoyed working. Though married for many years, he resented his new identity as husband and chauffeur for his wife’s frequent shopping trips.

The strengths for the participants in this study were largely in the form of ability to adapt physically, psychologically, socially and spiritually within the context of familiar environments, such as their own homes, the day hospice. Their social encounters and life patterns aided them in anchoring themselves to a known reality giving a sense of control real or perceived. Of all the participants, Hilda, Robert and Ethel were most noteworthy in this regard. Hilda drew upon her war-time experiences of suffering and struggle as a method for coping with her current problems. This apparently enabled her to normalise her expectations and experiences of the cancer. Robert anchored himself to his technical and practical resourcefulness. Ethel similarly demonstrated a dynamic and responsive adaptation to her change in physical ability and resources. Ethel was identifying herself as a creative and adaptive person as if this was part of her normal life trajectory.

Retirement in the main was the common factor which all these participants shared and in the main they appeared to draw upon their younger working selves help them to cope and adapt to their current situation, living with cancer and pain. It was mostly their younger selves with which all wished to be associated and identified.

6.2.4 Dislike of Analgesia

The apparent dislike of analgesia was common to all interviewed. A complex relationship with the taking of analgesia was apparent for all the participants. The degree of dislike varied though and for some the dislike of analgesia was hard to extract from a general issue with taking medication. Analgesia was variously responsible for compromising mental acuity, causing unwelcome side effects, demonstrating weakness or something to keep for only the worst possible pain.

Both Hilda and Dougie were vehement about their contempt for analgesia but both were observed in pain and taking analgesic medication. In the case of Hilda, she had asked the attending nurse for painkillers prior to the recorded interview and yet, whilst on tape, denied either ever having pain or ever needing to take any pain relief, suggesting that discussion of the need for analgesia was something private and not to be shared:

‘Yeah, I keep it just in case, but that’s in case...’

(line 128, 11)

Hilda was a good example of apparent stoicism and wishing to avoid being viewed as weak. She did not wish to appear vulnerable and implied that morphine could impair her judgement rendering her less capable of decision making. Perhaps, therein lay the explanation for her protestations, fear of being less mentally able or thought less mentally able by others. This was alluded to in her comments about her daughter not making decisions for her, without her:

'I can decide for myself...(the doctor) should tell you (not daughter)
what they're doing...'

(line 255, 11)

Dougie, like Hilda was clearly in pain whilst being interviewed yet he also was interviewed stating that he did not take analgesia (line 440, 08). Dougie had earlier described the pain he had in his abdomen and in the middle of the interview he had to get up to take medication for this. Dougie implied that his music, alongside his Christian faith, helped him to cope with pain particularly in the night:

'...what I do I just wake up and put my tape on, and sit in here - I
can't lay down doing nothing.'

(line 38, 08)

John in apparent response to the cancer diagnosis, described himself as the tough fighting miner who did not wish to be regarded as a 'sissy' and yet he complained of pain and reluctantly took the provided analgesia when offered. Was taking analgesia demonstrating some sort of weakness, did taking the analgesia imply some loss of control or was John simply trying to re-frame his life and identity in light of being old and having cancer?

John was clear that he preferred to do other things such as gardening or other activities in preference to taking analgesia:

'...what I can control, it seems to work'

(line 227, 05)

The main reason that Robert disliked his analgesia was that he could not eat when he took any of the stronger tablets because they made him very nauseous. The dislike of analgesia because of side-effects was not unique to Robert, Ernest was the most vociferous in his account of problems associated with taking analgesia. But, in Robert's case food was also comfort to him and the idea of not eating was abhorrent. He almost regarded his food as therapy in his use of metaphor and language to describe his food.

Ethel was reluctant to take analgesia and implied that if she took it too frequently it would not be as effective 'if she really was in pain'. She also did not find them very effective, hence her reluctance to take them. They also made her 'feel really ill' (line 32, 01). Eric had more faith in the effectiveness of his options for pain treatment but, felt that he should save any analgesia or radiotherapy treatment for his pain for when 'he really needed it' (line 365, 06).

The range of available analgesics and the possible combinations would suggest that none of these people should have been fearful or afraid of taking analgesia. However, taking the analgesia appeared to be at times disempowering. The complex relationship with analgesia related to fears of impaired mental ability, showing weakness to others, justifiable anxieties over side-effects and the need to hold something in reserve for when things might get worse.

6.2.5 Denial of pain.

The participants denied their pain in several ways. First, pain was not always expressed in the language which one might expect. Discomfort, ache and other less commonly used words were used to encapsulate or endorse the personal accounts. Hilda talked of 'much trouble' as a substitute for pain, John used the term 'hurt' and Ethel talked of 'having a bad day' alongside her aches. Indeed, the word *pain* was troubling for some of the participants. Fred mentioned pain in his diary but face to face at the interview he would only talk of 'discomfort'.

'I've written down all the aches and pains I get, but I don't think any of them will be to do with cancer'

(line 7, 07)

Robert similarly preferred the term 'discomfort' rather than saying he was in pain:

'...the only discomfort I have is from being diabetic and having kidney failure'

(line 179, 04)

Denying pain might equate with avoiding doing something which may cause anxiety, for example, taking strong opioids such morphine and losing control as exemplified by Hilda. Hilda's fear of taking analgesia was related to her fear of being seen as weak. In taking opioids she might be viewed as vulnerable and not the independent 'iron lady' from the interview. Analgesia, particularly morphine and other opioids, can be harmful in quantity as reflected by Robert's account of taking too much (line 75, 04). Robert denied his pain until it became so troubling that he took too much analgesia and slept for over two days. He played down the possible disastrous effects of an overdose:

'Yes, yes, I took a little bit extra of the morphine solution, that helps,
this is a good painkiller but it also enables you to get some sleep ...'

(line 332, 04)

Hilda was very concerned to be in control of her life and in admitting to pain she might have conceded some need for help from family members which she did not really want (line 248, 11).

The participants, when interviewed, said different things about their pain throughout the interviews which did not always correspond with either the diary or conversations before and after the recording. Perhaps they did not realise that this might appear inconsistent and it is likely that all their accounts reflected their feelings at the point of writing or speaking. However, time and context may have influenced what was said and written. Perhaps the participants did not wish their true feelings recorded or what was shared in the interview was not the whole picture of their experience, reflecting the complexity of their individual pain experiences.

There may have been pain and distress in the retelling of painful experiences; hence a reluctance to share those lived experiences. In revealing and concealing parts of their lives they were perhaps trying to retain some control and through denying their pain they were hoping it might resolve. In denying the pain they were not giving cancer any power and were keeping some control. In accepting the pain they were accepting the cancer, their prognosis, and 'giving in' as exemplified by John's words: 'I never let

anything lick me, put it that way' (line 131, 06). Regardless of this conjecture, words, however expressed, are clearly a limiting factor in the appreciation of another person's experiences of pain.

Denial or deferral of prognosis was sought by most of the participants. An example of this was found in Bob's expression of his pain and the way he grasped at the chance of being involved in a research project for a new myeloma treatment, as noted earlier in this chapter. The desire to 'give something back' gave Bob a renewed optimism and strength. In feeling valued as part of the trial he appeared to have found more resolve and resilience to the pain; it also gave him a purpose and the illusion of a 'cure'.

This denial of pain was a common theme which was frequently contradicted by a variety of different things that were observed by the researcher or expressed by the participant. Pain, expressed in a variety of forms, also reflected multiple manifestations and multiple dimensions of the experience. Indeed, the complex physical, emotional and social needs of all the participants further complicated the perspective. One of the apparent reasons for denial was related to the image of self which the person desired or needed to present. The idea that pain was showing weakness or vulnerability was shared by Fred and Hilda.

Fred in particular had kept a diary in which he made frequent references to the pain he experienced every day and every night:

'Aches and pains during the night, pain in right side, left leg, lower right leg and foot' and 'back pain during and after tidying'

(line 34, Diary 07)

These pains were consistent and very troublesome for Fred, as noted in his diary. However, in the interview Fred was adamant that the pain, if any was nothing to do with his cancer:

'I've got a lot of aches and pains, but I don't think they're anything to do with the cancer. The cancer was lymphoma and when it started, well, it just knocked me out. I was just worn out, but I wasn't in pain, and then with the chemotherapy, mostly it was like being sick and being absolutely without energy, but there wasn't physical pain, other than my age, you know, I'm wearing out! So most of that I've written in there, I've written down all the aches and pains I get, but I don't think any of them will be to do with cancer.

(line 2, 07)

In these remarks Fred appears ignorant of the possibility that the lymphoma might cause pain.

Hilda was vociferous in her denial of pain whilst being recorded and when asked directly about her pain she said:

'Not with my stomach, I have plenty trouble with my breathing, but with my stomach I have no trouble at all. I don't think there's anything wrong with, my surgeon say, not surgeon the GP, they call me iron lady'.

(line 36, 11)

Hilda was proud of being called 'iron lady' she used this to reinforce her self-perception of strength and resilience to resist the pain.

The concept of pain, held by each participant, had different meanings and interpretations; one of which was suffering. The concept of suffering was exemplified by Ernest who was apparently suffering with all the losses and his awful symptoms, including pain, yet he desired to be again the tough soldier that he had been. In contrast Hilda, did not use the word pain, and used the phrase 'plenty trouble' instead on several occasions. Indeed, using the word 'pain' proved challenging in the cultural contexts of each of the participant's shared lived experiences. This was evident in both the language used, most of the participants favoured terms such as 'hurt', 'discomfort'

and 'ache', and the reticence to express the word 'pain' in the interviews; perhaps reflecting the diminished power which they ascribed to the cancer.

6.3 Summary

This chapter has considered the wider experiences of all the participants.

The participants all had unique interviews which relate their moment of exposure to the researcher. The major themes, and supporting descriptions, identify the importance of being respected as an individual and of being listened too. The strong implication from these data is that good communication, using an individualised approach to enjoy the trust and confidence of individuals, is essential to gain any insight into lived experience.

All the participants drew heavily on their life experiences and biographies to give context to their current experiences. They preferred their identities as older people, perhaps this was less traumatic than presenting themselves as people living or dying with cancer. Blaming their 'old age' or the various cancer treatments for their pain and other distressing symptoms was favoured over blaming the cancer directly.

Striving to be in control and independent was fundamental to the participants' expression of their lived experiences of cancer pain. Expressing this control took the form of detailed descriptions of adapting daily activities, or coping with the pain, to live independently and avoid dependence on others. The use of biographical accounts endorsed participants' identities and was an expression of social identities, continuity, adaptation, grief and loss.

Analgesia was apparently disliked. The need to hold some analgesia or treatment back as a reserve option was an interesting justification for not having the analgesia or pain relieving treatment or perhaps for staying in control. Acknowledging pain might similarly show weakness or give 'power' to the cancer was a concern expressed directly or indirectly through metaphor.

The next chapter considers the major themes in comparison with other research findings and explores the wider issues related to this study.

Chapter 7

Discussion

7.1 Introduction

This study set out to consider the lived experience of older people with cancer pain accessing specialist palliative care services. Chapters 5 and 6 were guided by the theoretical principles and application of Interpretative Phenomenological Analysis (IPA). In these chapters a number of findings were set out as superordinate themes within cases and overarching major themes across cases. The major themes from chapter 6 were particularly useful to give a focus and structure to the discussion of findings and their implications.

This chapter considers the major themes and findings of this study. It details the implications of the findings and the overall strengths and limitations of the study. This chapter also demonstrates the theoretical, methodological and practice contribution to the current knowledge base.

The chapter begins with a summary of the findings of the study. It then explicates the major themes by relating them to existing knowledge and relevant theories as described in chapter 2. This is followed by a discussion of issues related to the research approach, challenges and methodological limitations. It further explores the limitations of the findings of this study, as presented in chapters 5 and 6, and the methodological concerns. The chapter concludes with observations on the implications of this study for practice, the contribution to the understanding of older people's experience of living with cancer and pain, and future research.

7.2 Summary of Findings

The aims and objectives of this study were addressed by application of phenomenology, through the tenets of IPA, using a diary-interview method. Interviews were conducted with nine older people, some of whom completed diaries to inform their interview. The analysis of the diaries and interview transcripts identified five overarching themes: 'better to be old than to be dying with cancer', 'maintaining control and independence', 'loss of identity-adapting and grieving for a former self', 'dislike of analgesia' and 'denial of pain'. The findings reflect the way previous life experiences were embedded and interwoven with pain and the daily practical activities of the participants. The themes demonstrate an alternative perspective on the word 'pain' and its embodied meaning of pain in daily lives. Each of these will now be examined in turn.

- Better to be old than to be dying with cancer

The participants variously attributed their old age or their cancer treatment for their pain and symptoms. Blaming the cancer or the treatment was apparently simpler and less traumatic for the participants. Relating their pain and associated experiences to the cancer was at times distressing.

- Maintaining control and independence

This study highlighted the importance and complexity of control and independence to older people with cancer and its significance to their lived experiences. It demonstrated that, when asked about living with pain and cancer, independence as part of being in control was an important factor for all participants. The achievement and maintenance of control and independence was identified as the most often cited factor and was significant in much of the interview narratives. Expectations and personal understanding of control and independence were dynamic in response to individual changing needs.

- Loss of Identity- grieving for a former self

Being old and having a cancer diagnosis was isolating for most of the participants. The impact of social isolation made some of the participants apparently introspective. Most drew upon their rich life histories, biographies and experiences to compare and contrast with their current selves and circumstance. In contemplating their former selves there was a considerable sense of loss and implicit grief.

- Dislike of analgesia

The dislike and possible fear of analgesia was tempered with general accounts of disliking taking any medication. The fear of strong analgesia, opioids in particular, was common to all participants. Most were reluctant takers of any analgesics, sometimes rationalising this with stoic references or fear of the loss of beneficial effect if too much was taken too early.

- Denial of 'pain'

There was a general unwillingness to acknowledge all pain and thereby give 'power' to the cancer. This dismissal or denial of pain was an apparently stoic presentation, common to most of the participants. The language and description of pain was frequently figurative and occasionally subtle within the interview data. There was apparent reticence to describe pain in common pain terms; this reticence seemed to relate to being in control.

7.3 Critical Reflection on Themes and Existing Literature

This section considers the issues arising from the findings and reflects on their relationship to the wider research literature.

7.3.1 Better to be old than to be dying with cancer

It was significant that all of the participants appeared to prefer to ascribe their symptoms to their age or the treatment for cancer rather than the cancer itself. It was particularly noticeable that this was apparently more socially acceptable to Ethel and

Hilda, the only woman amongst the participants. Indeed, gendered experiences of cancer pain are inconclusive in a younger adult population and nothing was identified in the literature review to support or refute this (Klepstad *et al* 2011). Describing their current experiences, Ethel explained that she had had a hard life and Hilda had lived through a war and many associated physical and mental traumas. For both Ethel and Hilda, when referring to their age, there may have been a conscious and purposeful self-stereotyping which helped them rationalise and cope with the pain and other symptoms associated with the cancer diagnosis.

Although all nine participants described the different effects, of being old, in the context of living with cancer and pain, there is no detailed exploration of these or similar accounts identified in current research. However, it has been suggested that that there may be perceived and actual benefits to the older person of self-stereotyping as old, in preference to being identified as the person with cancer, as it may help to modify their expectations and approximate these towards the expected norms of ageing (Levy 2003). Levy's programme of longitudinal research, with 660 older people, on age stereotyping endorsed that these stereotypes can influence older people's behaviours and responses in both negative and positive ways (Levy *et al* 2002).

All of the participants identified themselves as old. The findings endorse that, although the participants found their prognosis important, they frequently wished to illustrate any limitations to their lives and independence with reference to chronological age rather than the cancer. This is congruent with Levy's Stereotype Embodiment Theory (SET) which has attempted to explain the processes and assumed benefits of self-stereotyping in older age. Levy's theory advances that ageism is an internal construct which, when internalised, becomes part of latent ageist beliefs about becoming old and being old (Levy 2009). Implicit to this theory is that something, such as disease, may trigger these internalised responses and become part of observable responses that fulfil the self-concept of being old. Hence the older people interviewed for this study might have been presenting an internalised ageism, a preferred identity, to fulfil the stereotype which they perceived was expected of them.

This concept of self stereotyping implies that there may be internal as well as external factors which can influence perception of self with some potential to influence the external factors for positive effect. However, limited references which do exist suggest that personal or self-stereotyping of old age is usually negative, cumulative and unavoidable (Eibach *et al* 2010, Kotter-Grühn & Hess 2012). It would appear that at times the participants in the current study chose contradictory expressions of self to consciously or unconsciously cope with a stressful alternative. An example of this was in Dougie's account; he found being presented as old as a preferable alternative to being identified as dying with cancer and made reference to his 'old age' as almost a coping strategy, which legitimised expression of pain.

The cancer treatment was also apparently to blame for some of the pain and other side effects of cancer and this was identified in the accounts of three of the participants Robert, Ernest and Bob. Ernest and Bob exemplified this; they experienced what they described as 'horrible' side effects from their treatment for myeloma and consequently developed severe peripheral neuropathy. They also both appeared to have a limited understanding about the way myeloma manifests and the effects of the thalidomide treatment.

The accounts of attributing blame described in this study were commonly conceptualised as feeling distressed about something over which there was little or no potential for control, which in this case, was their chronological age or the cancer treatment. Specifically, blame was attributed to the chemotherapy and surgical interventions undergone. Similarly, recent studies and reviews related to surviving post cancer treatment and the concept of 'survivorship' are beginning to make some acknowledgment of the long term deleterious effects of cancer treatment (Miller & Triano 2008, Armes *et al* 2009, Siegel *et al* 2012). There is clearly a wider issue of ensuring that older people, in particular, are fully informed of the benefits and risks of their treatment. Thus, it is not unreasonable to consider the depth and breadth of information which is needed to support and ameliorate the anxieties of older people with cancer.

7.3.2 Maintaining control and independence

Control and independence are associated with an individual's physical ability to perform tasks, as in this current study. Cancer has been noted to have a significant effect on independence (Macmillan Cancer Support 2012). The goal of independence for older people has been described as important in promoting wellbeing, dignity and quality of life (DH 2001a, Audit Commission 2004). All the older people who participated in this study related accounts of maintaining control and independence; they described their daily existence and the attributes which enabled maintenance of this independence.

The participants in this study were all living independently, not in institutional care, and the struggle to maintain independence was part of their lived experience and desirable to their sense of selves in terms of quality of life and functional ability as demonstrated in the accounts of Ethel, Fred and Hilda (section 6.2.1). The accounts related included details of changes and adaptations made in the areas of mobility, household chores, personal care, social and leisure activities; presented as real or perceived control over maintaining their feelings of independence.

Consistent with the tenets of phenomenology and the lived experience, maintaining control and independence was the one particular theme or concern with which each participant described themselves. This finding also revealed the details and significance of adapting and coping strategies which shaped and informed their social and environmental context. The participants adapting and coping strategies included a level of critical self awareness in acknowledging their self-care limitations. It is unclear whether this was already known to them or whether the cancer diagnosis made them develop this clearer appreciation of self in order to adapt to stay independent.

These descriptions of self and control over independence partially reflect the wider research evidence that pain can impede independence but, do not explain the efforts the participants made or the significance in the daily lives of the participants in this study (Portenoy & Lesage 1999, Lin *et al* 2003, Deimling *et al* 2005, Kroenke *et al* 2010,

Rustøen *et al* 2013, Deandrea *et al* 2014). However, this current study noted the first-hand accounts whereas Rustøen noted the observations of nurses. Lin *et al* (2003), Deimling *et al* (2005) and Kroenke *et al* (2010) all talked to participants directly to determine any correlation between pain and independence; but no detail about the effects on the individual are noted. None of the qualitative studies included in the review in chapter 2 identified control or independence as a theme.

All the older people in this study talked openly in terms of their independence with specific examples of adaptation and dependency alongside their experiences of pain, fatigue, grief and loss. The combined effects of adaptation and coping with the pain contributed to accounts of loneliness and contentment or resentment about personal circumstances contrasted with needs for support or intervention; as noted in the accounts of Eric and Ernest in particular (Section 5.2.1). This presented a complex picture of the effects of pain and cancer on their daily lives where being in control, independence, dependence, autonomy and care needs were unique to each participant. This focus on activity as part of perceived control is similar to the findings of Bostrom *et al* (2004) where those with cancer, in receipt of specialist palliative care, needed an opportunity for dialogue with health professionals to express their personal circumstances related to independence.

The participants appreciated being listened to both as part of their cancer management and in relation to their needs for independence. In describing their independence, all of the participants made a point of emphasising their need to stay in control of their daily activities and health decisions as noted in chapter 6. Moreover, the fear of losing independence appeared to be related to autonomy and locus of control. Participants experienced this within encounters between themselves and their spouses or other family members, describing conflicting perceptions of need. The evident fear of dependence presents a powerful motivating factor which contextualised much of the interview data. This is congruent with earlier findings, as noted in chapter 2, where some of the oldest old identified that maintaining a sense of control was part of a coping strategy to maintain independence (Wilken *et al* 2002).

When describing their need for control, two of the participants, Ernest and Bob, gave particularly harrowing accounts of the effects of both the cancer and the subsequent treatment, neither of which could be attributed solely to age. The language used to describe the bony overgrowth and subsequent neuropathy was both directly and symbolically representative of their powerlessness. Ernest and Bob's stark terminology was also used to show the profound, and associated emotional, trauma of the prognosis alongside the experience of disease symptoms. The threat of dependence, for these men, was a driving factor in their accounts with the discomfort of living with cancer. They were coping with an uncertain future balanced with the desire to minimise dependence on others.

Examples of control, of self and circumstance, to maintain independence were related variously by all the nine participants. Detailed accounts of adapting and coping were exemplified by Eric (section 5.2) who was the most physically disabled, in terms of mobility, his descriptions suggested that maintaining the illusion of being in control and feeling independent was almost as important as being independent. It is plausible that the various accounts of maintaining independence were outward representations of how all the participants kept in control of their lives. This perceived self control and activity to aid coping were also observed by Thomé *et al* (2003) and Bostrom *et al* (2004) as noted in chapter 2.

Much of what was stated about independence in this study was conveyed in the context of coping and adapting. The older people in this study appeared to be versatile and had used a variety of methods to adapt and cope with the cancer, the treatment and associated symptoms, to maximise their independence and minimise the effects of any losses. For participants, Ethel, Robert, Eric, Dougie and Ernest, when describing coping strategies they presented references to previous experiences of controlling managing illness. These methods were varied, coping strategies included music and food, and their application was idiosyncratic.

In presenting their unique coping styles, strategies and preferences the participants were also showing the importance of identity beyond their diagnosis and chronological

age. One of the participants, Robert, was vocal about his use of food as comfort. Preparation of food was also his exemplar of independence; perhaps food was the one thing over which he had sole control, this was a highly personal and individualised experience. There is no specific research evidence which describes the importance of food, for those with a cancer diagnosis, but more generally food consumption has been shown to have effects on emotions and cognitive function (Kroesa *et al* 2014). Similarly, food deprivation has been associated with increased pain sensitivity (Pollatos *et al* 2012) and the use of food as analgesia has been noted to have an effect on pain perception (Zmarzty *et al* 1997, Zmarzty & Read 1999).

Another participant, Dougie, described the importance of music, either secular or religious, in his daily life and when coping with pain. It is important to consider whether this could be considered as part of an holistic approach to managing pain. Dougie proudly shared his use of music as an exemplar of his engagement with culture as part of his identity. Indeed, music has a wide anecdotal association with emotional experience and there is some evidence to suggest that music may effect neurological changes as well as subjective personal experience (Menon & Levitin 2005). However, the Cochrane Review published Music for Pain Relief in 2006 (awaiting update) and stated that there is insufficient evidence to conclude that music has any clinically measurable effect on the experience of pain (Cepeda *et al* 2006). Hence, further exploration of the benefits of music on the experience of pain is needed.

Five of the participants (Fred, Dougie, Ernest, Bob and Hilda) identified themselves as religious and made some reference to their faith as part of coping with the cancer diagnosis and having pain. In chapter 2 Cohen's study of older US and Israeli's noted the importance and cultural significance of religion in the older Christian Americans but not the Jewish Israeli's in their accounts of coping with cancer pain (Cohen *et al* 2005). However, in the current study, this religiosity is perhaps reflective of the age group and not necessarily applicable to a wider more secular adult population in the UK (Census 2011). In the UK spirituality and religion, as an intervention at the end of life, has been the subject of a recent Cochrane Review. The findings of this were

inconclusive because of challenges in defining terms, under reporting of methods and the personal nature of religion and spirituality (Candy *et al* 2012).

The importance of spirituality or faith may reflect that cancer pain has been conceptualised as total pain.³⁸ Pain has been considered as physical, emotional, psychological and spiritual (Delgado-Guay *et al* 2011). Older people, in particular, have been noted to rely on their religious faith to help them cope with illness (Murray *et al* 2004) and faith has been associated with stoicism (Pellegrino & Thomasma 1993, Cochran 2010, Shilling & Mellor 2010). Indeed, much has been written about the unmet spiritual expectations and needs of people with advanced cancer (Pearce *et al* 2012, Peteet & Balboni 2013, Höcker *et al* 2014, Piderman *et al* 2014). As such, the implications of faith on pain and the illness experience are clearly worthy of more consideration.

It is apparent from the findings, described in chapters 5 & 6, that independence is a construct or perception of the individual participant and it is reflected to greater and lesser extent in the other major themes. Maintaining control and independence, as described by the participants, was a personal, mutable and fragile concept and one which the older people wished to present and hold on to. Independence was contextual both to time and place in the narrative accounts. The analysis in chapter 6 appears to support theories that pain and cancer have an effect on independence; this is endorsed by the way that the participants in this study incorporated perceptions of independence in their narrative accounts as they made sense of the lived experience of cancer pain.

The older people in this study all wanted to stay independent but had significantly differing perspectives on being and maintaining their independence. Indeed, independence is a challenging concept to define, from any perspective, because of its subjectivity and synonyms are frequently applied including terms such as resilience, autonomy and quality of life (Hardy *et al* 2004, Nygren *et al* 2005). A challenge for

³⁸ Spiritual pain is a term which evolved from Dame Cicely Saunders' conceptualisation of the total pain of cancer (Saunders 1988).

future research is to define independence in terms which are acceptable from both an older person's and health care professional's perspective.

7.3.3 Loss of Identity- grieving for a former self

Another major theme of this current study was the presented loss of identity and purpose in the lives of the participants. The pain and distress of the cancer diagnosis and subsequent prognosis had clearly compromised their identities. For this study, identity was projected through detailed description of lives and justification of independence, as noted before, but more emphatically in accounts of personal loss.

Understanding the importance of identity from the perspective of the person with cancer may enable greater empathy with feelings of loss and grief for a former self (Ferrell et al 1995, Yamada & Decety 2009). Many references, in the current study, were made by the participants to previous life experiences to give context or explanation to the current experience and were part of the temporal journey of lived experience. Reflections, on their former selves and the intrusive effects of having cancer were part of personal accounts. Within these accounts social contexts were divided into two: the lives lived pre and post cancer diagnosis.

Social roles and position, expressed through biographical accounts, were central to the identities of all the participants in this study and helped to maintain their perceptions of self without which they felt less valued and valuable to society. This was exemplified by Eric, who had lost mobility with the cancer and later by Ernest who was protective of his remaining, if limited, abilities; both of whom felt that this had led to a kind of social rejection which compounded their feelings of grief and loss for their former selves.

These accounts appear to reflect the disruptive nature of cancer in a life-story; a personal and unique history. Indeed, Bury, in his 1982 study of adults experiencing chronic illness established the phrase 'biographical disruption' to conceptualise the way people experience illness (Bury 1982). He also described the taken for granted

assumptions, behaviours and disruptions in normally used explanations for illness experience and how this challenged self-identity. All the older people in this study gave accounts of how they revealed and concealed aspects of their lived experience with cancer and occasionally withdrew as part of their adaptive and coping processes for living with cancer. Robert's account illustrates this in the way he described withdrawing to his bedroom for two days and 'dosing up' with pain killers (Section 5.2.1).

The events of noticing symptoms, seeking medical advice and receiving a diagnosis formed a strong thread within and across participant accounts. Alongside accounts of independence and narratives of self there were some strong and indirect references to how the cancer and pain had disrupted their lives, as noted by Fred and Dougie in particular. More recent research, about living with cancer, has considered the issue of biographical disruption but with minimal focus on the concerns of older people in particular (Leveälähti *et al* 2007, Sinding & Wiernikowski 2008, McCann *et al* 2010, Reeve *et al* 2010, Hubbard & Forbat 2012, Wenger 2013).

Other studies have made similar observations to the current study about expression of perceived loss of identity and have related this to the existential anxiety of the disintegrating or decaying body (Baldwin & Wesley 1996, Murray *et al* 2005, Whittaker 2010). Indeed, decline is a normal part of the ageing process; however acceptance of disease or illness is more poorly explored (Twigg 2004). Another area of concern arising from the findings of the current study is that some of the presented concerns about identity and loss made the participants appear weak and vulnerable, something which they made efforts to disguise. This was exemplified in the accounts of Robert and Dougie who both described their loss of identity, and deftly gave accounts of how, despite their decaying bodies, they appeared to overcome their vulnerability.

However, there is evidence of an apparent counter narrative in these biographical accounts, that of continuity and the desire to hold onto the known as part of a normative ageing process as clearly demonstrated in Hilda and Robert's accounts. Congruent with the premise of Atchley's Continuity Theory (1989), the older people

interviewed for this study made many references to their strategies for holding on to and reinforcing the familiar in their lives. Continuity Theory has been described as an evolutionary process related to a personal construction of self which relates to perceived strengths and ability.

“...continuity is thus a grand adaptive strategy that is promoted by both individual’s preference and (in seeking) social approval.”

(Atchley 1989:183)

In this study the need for continuity was a subtle but clearly discernible interpretative finding, common to all, but not always as dominant as the disruptive accounts of their cancer and pain experiences.

All the older people, interviewed for this study, were clearly individuals with their own experiences and expectations, who did not want to be labelled by illness, condition or need. Almost all of the older people seemed to be mourning the loss of their former selves alongside examples of the pride they held in their younger pre-cancer identities. Bob was the exception to this and had an apparent enormous reserve of resilience. The loss was manifest in loss of social networks, friendships and opportunities to create new social encounters all of which had been part of their former lives before cancer. The continuity was expressed in part through biographical accounts but also in the maintenance and rediscovering of social networks, roles and friendships. Indeed, there may have been a positive effect in that having a cancer diagnosis had highlighted their chronological age and allowed them the right to explore and reflect on their lives, to talk about their identities and losses.

In an apparent display of grief for themselves, some of the participants may have been reflecting on their own mortality and morbidity. This may have been a kind of anticipatory grief for expected loss. Ernest’s account depicts this as it was heavily focused on his personal grief following the diagnosis with myeloma. This notion of anticipatory loss is more frequently described amongst care givers than the care

recipient (Higginson & Constantani 2008, Holtslander & Duggleby 2009, Anngela-Coe & Busch 2011). Anticipatory loss is only occasionally described in those living and dying with cancer (Mystakidou *et al* 2009, Cheng *et al* 2010). The complexity of grief and loss in advanced cancer patients makes this a challenging area of study particularly as grief has been noted as frequently associated with depression (Jacobsen *et al* 2010).

7.3.4 Dislike of analgesia

All the participants had a complex relationship with their analgesia which outwardly manifested as an apparent dislike, and they wished to have some power and control over their own pain management. Taking analgesia was variously described as affecting cognitive function, a weakness, something which might demonstrate vulnerability, something to be avoided because of side effects, only for the worst pain, keeping something in reserve, and something which might not be effective if taken too often.

The accounts of the older people in this study, which relate to analgesia and medication in general, correspond with extant research which identifies older people as poorly compliant with treatment regimens. Several studies have reported that older people are reluctant takers of medication (Lansbury 2000, Pound *et al* 2005, Banning 2008). The participants in this study did not want to take multiple medications, with some fearing they might lose control.

The problem of non-adherence with prescribed medication may be caused by legitimate concerns over adverse effects as noted in a recent systematic review and synthesis of the evidence base (Flemming 2010). World Health Organisation data supports the claim that non-adherence with prescribed medication is widespread and not confined to older people (Holloway & van Dijk 2011).

Within this study, participants also had an active dislike or fear of taking analgesia. Analgesia was regarded with contempt (Chapter 6 section 2.4), something reluctantly taken or to be avoided. Indeed, fear about taking specific medication, or multiple

different medicines, may have some justification. Polypharmacology, in a recent study of 385 older people (≥ 75) with cancer, was noted to be associated with frailty, increased hospital admissions and mortality (Turner *et al* 2014).

Concerns about the use and abuse of opioids and other drugs may have influenced some of the fear and dislike of analgesia which was observed in this study. The prescribing of morphine, in particular, has a legitimate and metaphorical association with tolerance, addiction and death (Willard & Luker 2006). Indeed, older people have been noted to be more reluctant to take analgesia than younger adults (Closs *et al* 2009). Thus, the reluctance and fear associated with taking strong opioids in this current study is comparable with other observations of older people with cancer.

The notion of keeping something in reserve for when the pain gets worse, as described by Eric, could also be considered in terms of control, real or perceived (Ranchor *et al* 2010). Control real or perceived in the context of cancer pain could be viewed as comforting (Vallerand *et al* 1997) but, has not been acknowledged in the qualitative studies of older people with cancer pain noted in chapter 2. Moreover, supporting and reinforcing this sense of control could be influential for a greater sense of wellbeing for those living with cancer or other potentially incurable disease (Ranchor *et al* 2010).

The more general concern that analgesia might become less effective is not unique to this study. The observation of tolerance of analgesia and concerns about non-compliance, in cancer management, are widely noted in the literature (Heidrich & Ward 1991, Aziz & Rowland 2003, Hewitt *et al* 2003, Luszczynska *et al* 2005, van den Beuken-van Everingen 2007).

7.3.5 Denial of pain

Denial of pain could be associated with fear of progression of the cancer. Breivik noted that people with can be reluctant to declare worsening pain as they feared this meant a worsening prognosis (Breivik *et al* 2009). In dismissing or denying their pain the

participants in this study appeared to be denying power to the cancer as exemplified in Hilda's account.

All participants in this study either denied or belittled their pain experience and some chose to describe or disguise their pain by reference to metaphor. The use of metaphor and the dismissal or denial of pain experience in the individual accounts could infer that most were stoic, hardy or resilient. Hence, in using terms such as 'tough' and 'hardy' the participants may have been trying to portray a meaning different from that which the researcher understands. In these initial interpretations and assumptions the researcher may have over generalised or perhaps been superficial in their interpretation. This reflects a culture and societal norm where stoicism is highly valued as it implies control and repression of emotions (Rutter 1985, Tusaie & Dyer 2004).

The participants drew upon their lived experiences of adversity and three, Fred, Ernest and Hilda, made particular reference to former roles and struggles. For all participants the sense of confusion and emotional trauma associated with the diagnosis and prognosis made the extraction of pain experiences complicated. Frank (1997) described the development of hope and resilience in the face of hardship and adversity as part of life-long learning. In this account resilience or stoicism might be seen as a mundane response to life experiences, correspondingly increasing with age. Indeed, the World War II generation³⁹ have been assumed to draw upon previous experiences of hardship to help them manage living with illness and disability in old age (Beard *et al* 2011, Young 2013). In comparison with the findings of the current study, this is a grossly over simplified model. However, most of the participants did identify themselves as children or adolescents during World War II and used this to endorse their accounts.

³⁹ The war generation or silent generation describes those who remember living through the austerity of WWII and the immediate post war years.

Three of the participants, Robert, Fred and Hilda, declared that they were in control of their emotions or presented an apparently inexpressive detachment to painful experiences and the lived experience of cancer in particular. Why some older people appear to present a stoic exterior is not well understood. Knowledge of the presented stoicism of ageing, and age related pain differences, are informed by limited primary research and mostly expert consensus (Helm & Gibson 1997, Hadjistavropoulos *et al* 2007, Herr 2011).

Two of the participants, Robert and Dougie in particular, chose to use metaphor either to elaborate or more remotely reference their pain experience. The use of metaphor or symbols to give meaning in illness and cancer discourse has been acknowledged (Reisfield & Wilson 2004). Metaphor use, particularly references to war and battles, can be illustrative and fundamental to normal expression of the experience because it is more tangible and visceral to the experiencing person (Penson *et al* 2004). Military metaphor has a long association with the need for a positive outlook and engagement with the need to survive following a cancer diagnosis, which in this study may simply reflect a desire to be hopeful, but also may infer passivity, compliance and emotional resilience (Loftus 2011).

Appreciation of metaphor may give an insight into the lived world of the person with cancer; it may be defensive and deflective, avoiding saying uncomfortable things directly or associated with fear, myth or stigma (Czechmeister 1994, Harrington 2012). However, metaphor may also be positive and hopeful. Indeed, cancer metaphor use is dominated by war and war related language (Hanahan 2014). This was strongly evident from the participants in this study as all made some direct or indirect reference to war either through the accounts of National Service or in battling the cancer.

7.3.6 Summary of Section

To this point the chapter has focused on the results of the study, the overarching themes and how they relate to, or contrast with, extant literature. This study attempted to grasp the complex and ideographic expression of the phenomenon of pain, yet some of the themes are more strongly evidenced in the data or have a closer similarity to other research findings. By implication there are parts of the participants' accounts which are not supported by the literature and there are areas of related literature which is not reflected in the participants' accounts of their lived experiences as summarised below.

- The problems of old age may be more acceptable to the individual rather than those of advanced cancer.
- Apparently blaming old age, as a self-stereotype, rather than presenting one's self as having incurable cancer is a coping strategy. This has not to date been acknowledged elsewhere and is a novel finding of this study.
- Cancer treatment may cause further pain and distressing symptoms which require explanation, support and management.
- Maintaining control independence, as a significant part of living with cancer and pain, is also a novel finding of this study; representative of a desire for control and certainty juxtaposed with fear of dependence.
- The way independence is maintained and revealed is unique to each person living with cancer pain and may be expressed through metaphor.
- Cancer had a disruptive and destructive effect on identity, lives and relationships, which is well documented in younger adult populations, but not elsewhere amongst studies of the old with cancer.
- The need for continuity, through biography and holding on to former identities, was also important.
- The older people in this study, similar to other studies of older people, were reluctant takers of medication and analgesia because of perceived weakness, concern over side-effects, developing tolerance or addiction.

- Being in control and keeping analgesia or treatment in reserve for worsening pain was a common notion and again novel to this study.
- Acknowledgment of worsening pain gives power to the cancer, is the implication of those denying pain, and is congruent with fears about cancer progression being identified by increasing pain.
- Apparent presentations of stoicism amongst older people may be convenient assumptions rather than fact.
- Metaphor use, particularly words related to war, may confound and complicate interpretation.

7.4 Reflexivity, Study Limitations and Consideration of the Whole.

As discussed in section 4.9, it is acknowledged that the researcher has considerable influence over the research processes and consequently reflexivity, as part of quality evaluation must be, undertaken (Willig 2008). Reflecting on previous experiences and understandings about the research question and how these may affect the research outcome is good practice in qualitative research. Reflexivity, and phenomenology in particular, requires the setting aside of prior assumptions and an attempt to 'bracket' the normal ways of approaching a phenomenon (Smith *et al* 2009). Thus the researcher must set aside their normal presuppositions, biases and prejudices so as to become open to the meaning in the expressed accounts of lived experience.

In attempting to 'bracket' prior conceptions, the first step was to acknowledge previous experiences and academic knowledge, in order to allow an honest insight into the participants' experiences. In keeping with the tenets of phenomenology and IPA this necessitated attempts at detachment from previous knowledge and experiences to 'bracket' pre-existing formal knowledge (Smith 1996). Husserl argued for a particular attitude where the (philosopher) observer attempts a degree of detachment from prior knowledge to see the essence of the phenomenon (Husserl 1913/1962). Engaging with this 'attitude' involved trying to see each encounter with a participant as individual and unique, noting what emerged rather than allowing any bias or prior experiences to prejudice each interview. In practice, during and after the interviews, the researcher tried to remain aware of what was brought to the interpretation and to keep this separate. The lengthy recruitment time was beneficial to reflexivity and the attempt to 'bracket' prior knowledge. The time, often weeks, between interviews and subsequent data analysis, provided a degree of detachment between participants. Keeping copious reflective notes before and, in particular, after each interview provided an opportunity to engage with any emerging thoughts and perspectives surrounding each participant and their account of lived experience.

However, complete openness to the essence of phenomena was not really achievable, because it is impossible to forget prior knowledge or to be completely new and fresh

to each experience. At best, the researcher can only claim to have maintained an open, empathetic and reflexive stance towards each participant. Empathy could be described as trying to understand from the perspective of the participant (Smith & Osborn 2008). The skill required to be empathetic has largely been gained by the researcher through years of working as a registered nurse. Openness was demonstrated through listening and allowing the conversation to be focused on the participants' needs and expectations. Reflexivity was achieved through use of note keeping, reflexive contemporaneous records, and the time taken to question how prior knowledge and understanding might affect understanding and interpretation.

The first issue related to personal reflexivity must be the choice of topic. The topic was chosen by the researcher, necessarily informed by personal experience, both professional and personal, and the literature in the areas of older people, cancer and pain. Moreover, the current public concerns of older people, their health care needs and apparent lack of support has heavily influenced the initial choice of topic. Indeed, it is probable that all these have in some way influenced data gathering, data analysis and theme development. Appreciation of the wider social and health care contexts is both a strength and a weakness. It is a strength because this study clearly responds to a limited evidence base and apparent unmet needs and a weakness because in this wider public context it is impossible to set aside existing the existing knowledge and experience of the researcher to see the topic without the bias of previous professional experience and assumptions as noted in chapter 1.

This latter point, about the bias of personal assumptions, reflects the context of the researcher as a social being. Experiences, and their understanding, are appreciated in the wider context and environment in which they occur. Thus sense making and meaning are contingent on understanding of self, our knowledge, experiences and the time and place of the event. As noted in chapter 3 this is considered in phenomenology by Heidegger as 'Dasein' or being in the world (Sheehan 2008:193). Humans are rooted in their cultural and social contexts, in this study a British and European world where older people and the ageing population are presented as needy and regarded by some as a burden on the health and social care systems. Knowing this

context puts a greater emphasis on awareness of the potential impact of this social context on conversation and interpretation.

External and personal human factors were also influential in the development of the methods and the process of data analysis. This wider social context, combined with personal, thoughts and emotions associated with the topic of older people's cancer pain may have influenced the encounters with the participants and subsequent theme development. Personal anxieties and concerns may have directly impacted on the interviews. More profoundly, experience as a nurse may have influenced the questioning. Nursing in a health care context may lead to an overemphasis on the illness rather than a wellness perspective (Vachon 2008). In attempt to ameliorate any preconceptions or illness modelling, the interviews were open and flexible to allow participants the opportunity to express their views and lived experiences without influence. This approach to interviewing was used to gain empathy and thus allow an unbiased representation of the voice of older people with cancer pain.

Finally, the accounts, language, expression and intonations used by the participants were distinctive and diverse and thus open to interpretation and misinterpretation. Indeed, pain is a unique and personal experience, known to the experiencing person and expressed to others but understood to have contextual subjective meanings. Thus, what the participants perceived and expressed, about what is apparently the same phenomenon, of living with cancer pain were different and were reported in unique ways. The accounts of each of the participants are consequently subjective interpretations by the researcher of the subjective accounts of the participants. This double interpretation or 'double hermeneutic' (Smith et al 2009), in IPA is the basis for the findings of this study and is thus a cautious presentation of the lived experience of older people with cancer pain.

7.5 Methodological Issues and Implications of IPA

This study has been informed by a qualitative and interpretative approach which is consistent with the tenets of phenomenology and IPA. The philosophical premise of IPA respects not only the individual nature of experience but the personal narrative account. IPA acknowledges that the words people choose to describe a particular experience may construct a version of that experience but, the same experience may be described in many different ways by the same person in different contexts (Burr 2003, Willig 2008).

The use of metaphorical and figurative language is closely associated with cancer in particular, yet the process of IPA assumes that all is interpretable and understood by the researcher (Harrington 2012). The expressions of pain used by the participants in this study were individual and probably highly cultural, associative or metaphorical, which implies that meaning and message may have been lost to the researcher. The analogies and references to previous experiences as detailed in chapter 5 endorse this possibility. Additionally, language, particularly English, has regional and cultural variations and may be supplemented by inflexions, pauses and non-verbal cues. The contemporaneous and reflexive notes kept by the researcher proved useful as did the rapid transcription and data analysis. In this, the researcher attempted to share the same understanding of the language, the words used and their meanings in a particular context.

The procedure of analysis in IPA directs the researcher to dissect and disassemble subordinate and superordinate themes, to reassemble for the individual and then to consider overarching themes across cases to establish meaning and gain insight into unique personal experiences (Smith *et al* 2009:220). Unless carefully and cautiously applied, this idiographic approach to the data may lead the researcher to forget the context, environment and chronological impact on understanding. In the current study therefore using this approach to the data analysis may have led to loss of information and shared meaning. This concern for the loss of the individual, the detailed and the

subtle in seeking themes across cases or individuals is shared by other researchers (Wagstaff *et al* 2014).

Merleau-Ponty proposes that human existence and experience is both intersubjective and temporal (Merleau -Ponty 1945/2009). Human experience is subjective to both the experiencing person and the observer and may change over time. Moreover, if one considers Heidegger's concept of 'life world' then temporality cannot be ignored as part of human existence (Heidegger 1924/2011). The implications of ignoring chronological sequence of thematic development may dislocate the superordinate themes from their temporal context and thus detract from meaning. In this regard, the current study can only offer a snapshot of experiences some of which were contemporary to the approximate time of participation. Thus, considering theme development in context and with the individual is closer to approaching the lived experience.

Finally, IPA is dependent on rich descriptions of experience (Smith *et al* 2009). On this basis, some of the participants might be considered unsuitable for inclusion in an IPA study, because their accounts could have been restrained or limited by the emotional pain and distress of having cancer. However, this argument would potentially exclude the inclusion of all people with advanced disease and it might be better to ensure that all participants are sufficiently supported and encouraged so that they can share their experiences.

7.6 Procedural Issues: strengths and limitations

This section details some of the concerns related to the conduct of this study, including sampling issues. The findings as presented in chapters 5 & 6 must be regarded within the context of these methodological limitations.

7.6.1 Sampling & Recruitment

One of the issues of this research was the problem of identifying people who were in pain. It is desirable to have a consensus of understanding of the way pain is presented

and described across all ages, cultures and socioeconomic groups. The presentation of pain was also a factor in the gatekeeping and selection of suitable individuals, the health professionals were the arbiters of who was in pain and applied the inclusion and exclusion criteria. It is therefore, important to explore further what factors might influence the health professionals' selection of participants, how they might identify people in pain and thus how suitable participants are identified. Clearly, these points relate to how pain is presented and perceived, in terms of language used and assumed suffering, and beg the question again of who is the arbiter of the person who is in pain.

Numbers of participants in any study are important. Given the small number of participants and the limited contact with each it is reasonable to assume that each case represents a snapshot or moment for that individual. Thus, the major themes may well be limited to that time and context. Indeed, had time and resources allowed it might have been beneficial to consider repeated contact with each participant.

The sample size in IPA is usually small to ensure the representativeness of each and relates to the idiographic approach to the data set, thereby ensuring that nuance and subtlety is not lost to the researcher (Smith 2004). In the current study a relatively small number of participants were accessed to allow detailed consideration of each case. Having a smaller sample in this study enables rich, thick, subtle and detailed analysis of data (Smith *et al* 2009). This may have restricted any application of the experience in a larger population (Willig 2008). The findings of this study may tell us something about the experiences of older people with cancer; however, they cannot be generalisable to all older people or to younger adults with cancer. Thus, the idiographic nature of IPA is both desirable and restrictive. On the other hand Willig considers that, regardless of the size of qualitative studies, experiences may be appropriate to a particular culture and society, and inform the generation of subsequent research (Willig 2008). Furthermore, in the tenets of IPA, Smith (1999) argues for the avoidance of generalisation and the significance of illuminating the individual account.

It was intended that the participants would be restricted to those aged ≥ 75 ; however access to older people was challenging as described in Chapter 4 and the recruitment parameters were revised accordingly. Despite the ageing UK population, older people are underrepresented in health care research. Increasingly healthcare research is attempting to include older people to ensure their needs are understood and met through movement towards a presentation of 'positive ageing' (Biggs 2001, McHugh 2003, Clarke & Warren 2007, Wiles *et al* 2011, Richards *et al* 2012). However, problems of access with this significant and growing minority group have been similarly noted by other researchers (Harris & Dyson 2001, Barnes *et al* 2005, Marcantonio *et al* 2008, Ridda *et al* 2010).

7.6.2 Study Strengths

The main strengths of this study lie in the choice of topic and the methods used to collect and analyse older people's pain and cancer experiences. Using a qualitative and open method of diaries and interviews, supported by the tenets of IPA, has promoted and endorsed the importance of giving older people a voice through the rich descriptions of their lived experiences of pain and cancer.

The methods used in this study encouraged older people to share their experiences and concerns in preference to their apparent medical needs and those assumed or predefined by the researcher. Using this approach resulted in rich detailed descriptions of this little explored area of older people's cancer pain experience. The resulting findings suggest potential areas for future research related to the experience of older people with cancer and pain and the potential insight this may have on understanding their needs.

Another strength of this study lies in the process of establishing rigour, how quality and trustworthiness were assessed. As discussed in the methods chapter (Chapter 4. Section 8.3), Tong's (2007) criteria were followed throughout the research process. Findings and analysis were regularly discussed with research supervisors and peers. This involved keeping detailed written records, the support and scrutiny of research supervisors and checking of data by representative of the NTCRN Consumer Research

Panel. This was also supported through use of keeping contemporary notes and a reflexive diary whilst conducting the research. The criteria for validity in IPA were closely applied to ensure that the interpretation was informed by the data (Smith *et al* 2009).

7.6.3 Study Limitations

The primary limitation is the limited applicability of the current study to other contexts and populations related to the definition of and subsequent accessibility of older people. The sample was necessarily small and thus any findings are not generalisable to a wider population. However, it was never intended that the findings would be generalisable to a wider population but rather that it makes cautious claims about a small population (Smith *et al* 2009). Other limitations relate to the processes used, which must be rigorous in their application and to the analysis which should be valid and trustworthy so as to ensure that themes are clearly reflective of a participant's experience.

Despite enthusiastic introduction, this study failed to demonstrate the potential benefits of using the diary-interview as a method. Diaries were accepted by the participants but largely not used as intended. This research method was based on the reasonable assumption that older people are the best representatives of their own lived experiences. It was intended that each diary would inform and structure the subsequent interviews and thus facilitate in-depth exploration of the participants' concerns. In practice, fewer diaries were completed than was anticipated. In the few instances where diaries have been used to consider pain, in people living with cancer, these have largely focused on ensuring compliance with analgesia regimens rather than considering the lived experience of pain or prospective, contemporary pain record to inform pain assessment (de Witt *et al* 1999, Miaskowski *et al* 2001, Broom & Tovey 2008). However, the successful use of diaries with older people is more widely noted in the research literature (Milligan *et al* 2005, Jacelon & Imperio 2005, Fudge *et al* 2008). Congruent with the findings of this study, Fudge recognised that age in itself is not a barrier to diary use with older people, rather physical and health related

problems which may limit writing ability. Hence, alternatives to paper diaries, for keeping a contemporary record, might be worthy of future consideration.

Given that some of the participants avoided use of the term 'pain', the use of a 'pain diary' might have been off putting or too limiting for the participants. As noted in section 4.3.1, pain or health diaries can be useful for the collection of contemporaneous or longitudinal data (Helme & Gibson 1998, Maunsell *et al* 2000, Morone *et al* 2008, Hager & Brockopp 2009). However, using a diary without the title 'pain diary' or pain related prompts might be more beneficial for future studies in order to explore lived experiences and to be open to the associated holistic needs of the individual.

The open interview was intended to encourage an authoritative personal narrative account of the required experience. However, the participants' freedom to explore areas in which their lives were affected by cancer pain may have had an occasional diversionary influence on the conversation. A future option would be to have a more structured, yet still flexible approach, keeping the questions sufficiently open. Indeed, adopting a flexible approach encourages a richer and more detailed account. This remains consistent with IPA which regards the participant as the expert on their own experiences (Smith *et al* 2009).

Regardless of these and any potential limitations, the overarching concern has to be that older people have such a limited voice in research about the experience of cancer, pain and health care research in general.

7.7 Recommendations and Implications from the Findings

In exploring the findings of this study it is important to consider how to best promote and support the unmet needs of older people with cancer and pain. An overarching consideration is the introduction of an approach to care and symptom relief, including pain management, which looks beyond the diagnosis and communicates that the whole experience of distress and pain is important and acknowledges that older people may not wish to engage fully with their diagnosis or prognosis. To facilitate this, the delivery of services should be individualised and person centred, encouraging older people to be empowered and to achieve a sense of autonomy and control. This message needs to be shared with all the professional and lay carers of older people with cancer.

The older people in this study represented a heterogeneous population whose health needs are best considered individually as is endorsed in the NHS promotion of person-centred care (DH 2001). The individual findings of this study are applicable to the nine participants interviewed, who were all White European. Further qualitative study is therefore needed to replicate this study in different older populations to consider how older people from different backgrounds, cultures and ethnicities experience cancer pain. Subsequent quantitative study may help to identify the extent to which themes arising from this study are representative of the wider population of older people with cancer pain.

For the purpose of future health care research and health care delivery it would be useful to have appropriate definitions of older people which reflect the massive chronological age range, the spectrum of physical health status and health care needs in this diverse and growing population. Similarly, having a working definition of independence, which acknowledges the personal and unique in each older person's perspective of their lived experience, would be beneficial for both health and social care providers.

The cultural and societal taboos of age, pain, cancer, dying and death are all embraced in the findings of this study and need to be addressed. These are all part of wider sociocultural barriers which need to be engaged with. In the first instance, education should be targeted at social and health and social care professionals to challenge the negative constructions of age, cancer, pain, death and dying so that communication is beneficial and older people are listened to.

A significant area of concern is how much the participants really understood about their treatment and how their analgesics could help them. Were they afraid to ask for alternatives if the side effects were not acceptable? Did they not all engage fully with the support provided by the local specialist palliative care services? By implication, significant education about the effects of various treatment options and analgesia is needed. Hopefully, future studies will also consider the importance of education and communication in therapeutic relationships to assist older people with cancer and pain to cope with managing their pain, and symptom experience, and associated challenges of living independently.

Therapeutic relationships require enhanced understanding of another person's, emotional, spiritual and psychological needs alongside physical illness and an appreciation of the lived experience of cancer pain. Studies which focus on the improvement of wellbeing and reduction of distress for those older people with cancer and pain should be encouraged so as to support the comprehensive holistic needs of older people.

7.8 Conclusion

This study has contributed to the body of research about living with cancer and pain through the approach it has taken to the theoretical, methodological and practical considerations of accessing older people who are in receipt of specialist palliative care services. In this undertaking it has added to the collection of practical knowledge and understanding of older people's experiences of living with cancer and pain.

For the older people in this study, control, independence and the prevention of dependence was a factor in their expression of their lived experience of cancer pain. But, the major finding of this study was the self-report of being old in preference to identifying as living or dying with cancer. Another notable concern was the unwillingness to give power to the cancer by acknowledging worsening pain.

Using the diary-interview method gave the participants an opportunity to write about their experiences noting a contemporaneous report, as well as enabling development of those experiences subsequently, through the interview process. However, the diary part was not as successful as anticipated. The personal diary and interview approach, where both were used, ensured that the data was both important and relevant to the participant and encouraged engagement with and reflection on the lived experience. For the most part using a relatively unstructured approach, to interviewing the participants about their lived experiences of cancer pain, allowed the production of rich, nuanced and detailed data and provided a glimpse into their life-worlds.

This study has given nine older people a voice to share their unique experiences of living with cancer and pain, and has added to a rich and deeper understanding of their lived experience. Through a phenomenological approach, this study has contributed to a more detailed understanding of the lived experience of cancer and pain, the challenges to independence and identity, the emotional effects and meanings attributable to the deleterious nature of cancer, cancer treatment and pain.

Cancer and pain fracture people's lives and for the older people in this study this was confounded by internal and external expectations of pain and ageing on their individual lived experiences. The effects on self and identity were particular and profoundly felt despite the multiple interpretations and influences of context and personal experiences, expectations and beliefs about older people, pain and cancer.

Despite the presented differences between participants, this study has established the importance of allowing older people to express their concerns and needs. When caring for older people in receipt of specialist palliative care, the priorities of care should be directed by the needs of the older people themselves as voiced by them and heeded in preference to general assumptions about the needs of older people or the needs of people with cancer. Listening empathetically, to engage with the older person as person first rather than 'old', may be challenging as self-identification as being old may be a useful coping strategy which can deflect attention from the distress of the cancer diagnosis.

The assumption that independence is always possible and desirable has to be challenged and should always be considered on an individual basis. To encourage understanding of individual needs, the use of diaries or other contemporary methods of recording daily experiences needs to be explored further. Contemporary records when combined with interviews could be used to give insight into older people's experiences of living with cancer pain as a valid and concomitant adjunct to conventional assessment strategies.

This study adds support to the idea that older people are not a homogeneous population and adds to the argument that chronological age is not the most important factor in approaching an individual's needs. It is in the appreciation of each older person's account of self and lived experience that this thesis offers an alternative perspective on understanding older people's needs when living with cancer and pain.

Finally, this study adds to the existing body of knowledge through considering the extent of the lived experience of cancer pain and provides a new and original

contribution to knowledge as no work has previously sought to consider the lived experience of older people with cancer pain through use of a diary interview method.

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Appendices

Appendix A

Search from Medline & CINHAL via EBSCO Host January 2015

S5	 (TX pain) AND (S2 AND S3 AND S4)	Search modes - Boolean/Phrase	 View Results (1,370)
S4	 TX pain	Limiters - Published Date: 19960101-20141231; English Language: Human Search modes - Boolean/Phrase	 View Results (392,964)
S3	 AB cancer	Limiters - Published Date: 19960101-20141231; English Language: Human Search modes - Boolean/Phrase	 View Results (608,364)
S2	 AB older people OR elderly OR Aged	Limiters - Published Date: 19960101-20141231; English Language: Human Search modes - Boolean/Phrase	 View Results (342,486)
S1	 AB older people OR elderly OR Aged	Limiters - Published Date: 19960101-20141231; English Language: Human Search modes - Boolean/Phrase	 View Results (2,560,241)

Appendix B Hawker Tool

Hawker *et al* (2002) – Score very poor=1, poor=2, fair=3, good=4

	Bennett <i>et al</i> (2009)	Bostrom <i>et al</i> (2004)	Brockopp <i>et al</i> (1996)	Cascinu (2003)	Cohen (2005)	Duggleby (2000a)	Duggleby (2000b)	Gagliese <i>et al</i> (2009)	Larsson & Wijk(2007)
Abstract & Title	4	4	3	4	3	4	3	4	3
Introduction & Aims	4	4	3	4	3	4	4	4	3
Methods & Data	4	4	3	3	3	3	3	4	3
Sampling	4	4	4	4	3	3	3	4	3
Data Analysis	4	4	4	4	4	4	4	4	3
Ethics and bias	4	4	4	4	4	4	4	4	3
Findings and Results	4	4	4	4	3	3	3	4	3
Transferability / Generalisability	3	2	3	3	3	3	3	3	3
Implications and Usefulness	4	4	3	3	3	3	3	4	3
Total Quality Score	35	34	31	33	29	31	30	35	27

Hawker Tool cont.

	Leydon et al (2003)	McPherson et al (2014)	Riley-Doucet (2005)	Ryan (2005)	Thomé et al (2003)	Thomé et al (2004)	Vogelzang et al (1997)	Wijk & Grimby (2008)	Yates et al (2002)
Abstract & Title	4	4	3	4	4	3	3	4	4
Introduction & Aims	4	4	3	4	4	4	3	3	4
Methods & Data	4	4	4	4	3	4	3	4	4
Sampling	4	4	4	4	4	4	3	3	3
Data Analysis	4	4	4	4	3	4	4	3	4
Ethics and bias	4	4	3	4	4	4	3	4	4
Findings and Results	4	4	3	4	3	4	3	3	4
Transferability/Generalisability	3	3	3	3	3	3	3	3	3
Implications and Usefulness	3	3	3	3	3	3	3	3	3
Total	34	34	30	34	31	33	28	30	33

Appendix C Model of Theme Development key- major themes, superordinate themes, subordinate themes

Control & Maintaining Independence	Independence : adapting and coping 01,	-adaptation to maintain independence 06	-Distraction 01	- tough & strong 05
Better to be old than dying with cancer	A reluctance to acknowledge cancer as the cause of any symptoms 01	-hope 06	-Walking 01	-caring 05
Loss of Identity- grieving for a former self	Reluctance to use Analgesia 01	-anger 06	-Pacing 01	-resignation 05
Dislike of analgesia	Identifying self through history and social encounters 01	-ambiguity towards the pain and treatment 06	-Safety 01	-loss of former self 05
Denial of 'pain'	Independence and control 04	-dislike of analgesia 06	-Diminishing experience 01	-dislike of analgesia 05
	Presenting himself as tough and independent 05	-the story of his diagnosis and his life story 07	-Need for non-cancer pain 01	-fear of analgesia 05
	Contrasting selves as impervious to suffering and sensitive parent 05	-grief for his former self 07	- need to justify use of analgesia 01	- coping, importance of activities 05
	Grief for his former self 05	-dislike of the word 'pain' 07	-fear of use of analgesia 01	-hope 05
	Biography 06	-loss of confidence 07	-biography 01	-blaming treatment for his pain rather than the cancer 04
	Old age to blame 07	coping 08	-nostalgia 01	-dislike of analgesia 04
	Other causes than cancer 08	-identity as a tough and capable individual. 08	-former self 01	-metaphor (food and gadgets) 04
	Distress 09	-dislike of analgesia 08	-family role 01	-loss of identity 04
	Anger and blame 09	-grief 08	-social life –importance of company 01	-faith & coping 09
	Grief for his former self 09	-biography 09	-relationships 01	-identity as father & husband 09
	Coping 09	-anguish at prognosis 09	- dismissing his symptoms 04	-issues related to painful hands and feet.10
	Independence 10	-blaming old age 10	-denial of 'pain' and cancer 11	-dislike of analgesia 10
	Resilience through faith and life experience 10	-dislike of analgesia 11	-loss of former self 11	-dislike of the side effects of the treatments 10

Appendix D Developing Superordinate themes -

Superordinate theme	Subordinate themes	Themes (line of transcript)
Need to blame other things than cancer	Coping	<ul style="list-style-type: none"> • Tough 118 • Important (Dog breeder & show judge) 186,242,856
	Dislike of analgesia	<ul style="list-style-type: none"> • Other causes of pain (not cancer)25,141
	Identity as a tough and capable individual.	<ul style="list-style-type: none"> • Faith 77,681 • Social existence 325 • Financial independence 802,894
	Grief	<ul style="list-style-type: none"> • Former self 302 • Wife died 191,516
		<ul style="list-style-type: none"> • Capable (DIY, hobbies etc) 269, 334, 564, 959 • Self esteem 151,358 • Pragmatism
		<ul style="list-style-type: none"> • Remedies "cider vinegar 225 • Music 39,444
		<ul style="list-style-type: none"> • Fear 879 • Girlfriend 713,863 • "others worse off" 202
		<ul style="list-style-type: none"> • Anger at lack of support for older people 794 • List of "can't do..." 145,346,483,531

Appendix E Extract from Interview with Dougie

Developing themes		Line coding
<p>Coping</p> <p>distress</p> <p>Adapting</p>	<p>How do you manage?</p> <p>Well I have a shower, that's another thing that upset me. They tell me there's all these places where you can get assistance, there's a lady on here. This week actually there's been four vans from council making her bathroom into a wet room and everything, and it's not council property. But her daughter works for the council, so they'll be paying for it.</p> <p>Would you like one?</p> <p>I've had a shower put in but it cost me £1,100, I couldn't get any help towards it from anywhere. I mean my brother up Scotland, he's just had his bathroom altered and everything because of his age and that, and the army paid for it, his regiment. And I've been a member of this soldier singles fund, I phoned the drill hall at Rotherham up to ask her for any help and there was nowt doing there. But they paid for all his. As I say I've earned every penny I've got, I don't get much back from it, but I had a shower put in last year.</p> <p>So you couldn't get in and out of a bath at all now?</p> <p>Oh no, I had to phone a neighbour up one day to get me out. I just couldn't move, I couldn't believe it. And where was it, oh it was Savoy at Blackpool, we went to Blackpool, and without thinking I climbed in bath, and when I'd had my bath I found out there were no hand rails on side.</p> <p>How did you manage?</p> <p>Oh I struggled for a while and got out, but it took me about an hour and half to get out.</p>	<p>Putting on a brave face</p> <p>pragmatism</p> <p>Anger</p> <p>Financial independence</p>

Appendix F. Iterative Data Analysis – Developing subordinate themes

Participant 01 (Ethel)	Participant 04 (Robert)	Participant 05 (John)	Participant 06 (Eric)	Participant 07 (Fred)
<p>Coping</p> <ul style="list-style-type: none"> • Distraction • Walking • Visitors • Keeping busy <p>Biography</p> <ul style="list-style-type: none"> • Nostalgia • Former self • Family role 	<p>Biography</p> <ul style="list-style-type: none"> • Former self • Important person • Clever person • History of diagnosis <p>Diminish or dismiss symptoms</p>	<p>Biography</p> <ul style="list-style-type: none"> • Tough & strong • Fit • Caring <p>Adapting</p> <ul style="list-style-type: none"> • Resignation 	<p>Biography</p> <ul style="list-style-type: none"> • Former life • Holidays <p>Change</p> <ul style="list-style-type: none"> • Disruption of pain 	<p>Biography</p> <ul style="list-style-type: none"> • Soldier • Tough • Runner <p>Story of Diagnosis</p>
<p>Loneliness</p> <ul style="list-style-type: none"> • Long days 	<p>Blaming treatment/drugs for pain</p>	<p>Grief</p> <ul style="list-style-type: none"> • Former self • Loss of greenhouse • Social life • Pub • Wife 	<p>Adaptation</p> <ul style="list-style-type: none"> • Loss of social life • Creation of new/ replacement activities 	<p>Grief</p> <ul style="list-style-type: none"> • For former self • Widower
<p>Adapting</p> <ul style="list-style-type: none"> • Pacing • Safety • Equipment • position <p>Blaming old age or other (not cancer)</p> <ul style="list-style-type: none"> • Diminishing experience • Need for non-cancer pain 	<p>Use of metaphor for pain and coping</p>	<p>Analgnesia</p> <ul style="list-style-type: none"> • Dislike • Fear • "Not a sissy" • Won't give in <p>Coping</p> <ul style="list-style-type: none"> • Importance of activities • Gardening • Greenhouse 	<p>Anger</p> <ul style="list-style-type: none"> • Pain and reduced mobility • Lack of (free) services for older people e.g. motability 	<p>Dislike of word "pain"</p> <ul style="list-style-type: none"> • Lots of discomfort described in diary • Lots of pain described in diary <p>Loss of confidence</p> <ul style="list-style-type: none"> • Importance of independence
<p>Analgnesia</p> <ul style="list-style-type: none"> • Need to justify use • Fear of use <p>Social Life</p> <ul style="list-style-type: none"> • Importance of 'company' • Relationships 	<p>Control</p> <ul style="list-style-type: none"> • Need to adapt • Technology- Gadgets • Independence <p>Grief</p> <ul style="list-style-type: none"> • Former self • Social life • normality 	<p>Hope</p> <ul style="list-style-type: none"> • Greenhouse • focus 	<p>Analgnesia</p> <ul style="list-style-type: none"> • Dislike • Saving it up for "if it gets bad" <p>Need for Normality</p> <ul style="list-style-type: none"> • Through activity • "getting out" 	<p>Blame old age</p>
<p>Independence</p>	<p>Coping</p> <ul style="list-style-type: none"> • Food metaphor 		<p>Need for alternative diagnosis (old age) and cause for pain</p>	
<p>Vulnerability V stoicism</p>				
<p>Hope</p>				

Iterative data analysis – Subordinate themes (cont)

Participant 08 (Dougie)	Participant 09 (Ernest)	Participant 10 (Bob)	Participant 11 (Hilda)
<p>Biography</p> <ul style="list-style-type: none"> Tough Important (Dog breeder & show judge) Capable (DIY, hobbies etc) 	<p>Biography</p> <ul style="list-style-type: none"> Tough Good father capable 	<p>Biography</p> <ul style="list-style-type: none"> Happy go lucky 	<p>Biography</p> <ul style="list-style-type: none"> Tough lady In WWII
<p>Blame old age</p> <ul style="list-style-type: none"> Other causes of pain (not cancer) 	<p>Anguish of diagnosis and prognosis</p> <p>Distress at losses/former life</p> <ul style="list-style-type: none"> Mobility soldier 	<p>History of diagnosis/prognosis</p>	<p>History of diagnosis</p>
<p>Coping</p> <ul style="list-style-type: none"> Music Faith Social existence Remedies "cider vinegar" Pragmatism "others worse off" 	<p>Identity</p> <ul style="list-style-type: none"> Husband Gardener Church warden/gardener 	<p>Painful hands and feet</p>	<p>Coping</p> <ul style="list-style-type: none"> Importance of Faith
<p>Adapting & Hope</p> <ul style="list-style-type: none"> Girlfriend 	<p>Adapting</p> <ul style="list-style-type: none"> "coping" Faith 	<p>Pain</p> <ul style="list-style-type: none"> Lots mentioned in diary Listed medication taken 	<p>Analgesia</p> <ul style="list-style-type: none"> Dislike Shows weakness
<p>Grieving</p> <ul style="list-style-type: none"> Former self Wife died 	<p>Angry/blame</p> <ul style="list-style-type: none"> Treatment too late & wrong "System"- ageism/anti cancer Side-effects painful mouth-bony overgrowth Neuropathy Social isolation of cancer 	<p>List of can't do</p> <ul style="list-style-type: none"> Wash pots Write easily 	<p>No "pain", denial</p> <ul style="list-style-type: none"> Described disruption Discomfort in stomach "It hurts here" Difficulty swallowing I don't take pain killers,
<p>Analgesia</p> <ul style="list-style-type: none"> Fear Dislike 	<p>Pain in feet</p> <ul style="list-style-type: none"> Damage excruciating 	<p>Blaming old age</p>	<p>Loss of former self</p> <ul style="list-style-type: none"> Independence Weak unable
<p>Hobbies</p> <p>List of "can't do.."</p>		<p>Dislike of side effects of treatment</p>	
<p>Anger at lack of support for older people</p> <ul style="list-style-type: none"> Financial Adaptations-paid for his own 		<p>Adapting</p> <ul style="list-style-type: none"> driving & outings for escape 	<p>Blame old age/non cancer causes</p>
<p>Self esteem</p>			

Subordinate themes-> Superordinate themes showing development of superordinate themes across cases

01 Ethel	04 Robert	05 John	06 Eric	07 Fred
independence through adapting and coping	independence and control	presenting himself as tough and independent	biographical accounts of his life-identity	old age rather than cancer was to blame
a reluctance to acknowledge cancer as the cause of any symptoms -Blaming old age	dismissing his symptoms	contrasting selves as impervious to suffering and sensitive parent -identity	adaptation to maintain independence,	the story of his diagnosis and his life story - identity
reluctance to use analgesia	blaming treatment for his pain rather than the cancer		hope	grief for his former self
	dislike of analgesia	grief for his former self	anger	dislike of the word 'pain'
identifying self through history and social encounters	metaphor (food and gadgets) loss of identity		ambiguity towards the pain and treatment dislike of analgesia	loss of confidence- (desire for independence)

Subordinate themes -> Superordinate themes showing development of superordinate themes across cases (cont.)

08 Dougie	09 Ernest	10 Bob	11 Hilda
need to have other causes for his pain than cancer- blaming	distress about his symptoms	independence	Faith & coping- independence
coping	anger and blame- blaming	issues related to his painful hands and feet.	dislike of analgesia
identity as a tough and capable individual.- identity	grief for his former self	dislike of analgesia	denial of 'pain' and cancer
dislike of analgesia	coping-independence	dislike of the side effects of the treatments	loss of her former self -identity
grief		blaming old age	

Appendix G

Research Protocol 21.9.12

Older people's cancer pain experience, a qualitative exploratory study

Mrs Margaret M. Dunham

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1. Project Details

Investigator details: Mrs Margaret M. Dunham

Supervisors: Dr Karen Collins
Dr Peter Allmark
Professor Malcolm Whitfield

Sponsor details: Sheffield Hallam University

2. Research Question

To consider how older people construct the experience of cancer pain and how this is informed by expectations and experiences.

2.1 Objectives

To understand the experience of cancer pain in older people

To illuminate underlying themes and contexts, that may account for this experience.

3. Abstract

The proposed study aims to capture the experiences of pain of older people with cancer, consider how the older people construct the experience of cancer and how this is informed by their expectations and experiences. This study considers the need to improve health care for older people with cancer pain by exploring the unique experiences of living with cancer and pain. Older people make up an expanding proportion of the UK population and older people are known to be disadvantaged in respect of healthcare provision. People with cancer aged over 75 years are most likely to present with advanced cancer at diagnosis and are a largely underrepresented group in UK studies. Amongst people with cancer, pain is a common and distressing symptom. Up to two thirds of people with cancer will experience moderate to severe pain. Furthermore, pain in older people is an acknowledged physical and therapeutic problem. Thus, the combination of cancer, pain and old age may be a significant concern. Additionally, cancer pain is often accompanied by other distressing symptoms such as fatigue, nausea, restricted mobility and therefore a reduced quality of life. As the incidence of cancer increases with age it is likely that the proportion of older people with cancer and pain will be large and will pose a major problem for the experiencing individual and consequently the health care provider. The nature of this problem is not fully understood and warrants further study. Older people's concerns need representation to guide communication which supports their needs and wants and informs planning of their care. To this end the researcher proposes a qualitative research study, though a diary interview methodology, to ascertain the experiences and needs of older people living with cancer pain. It is hoped that a daily diary of

pain experiences, followed by an interview prompted by the contents of this daily diary, will help the older people to note and explore their thoughts, emotions, concerns and the effects on daily activities with the researcher.

4. Background

Cancer is more prevalent in older age and the number of older people in the UK population is anticipated to increase to represent 22% of the adult population by 2031 (Cancer Research UK 2008, Office for National Statistics ONS 2009). The risk of cancers, such as breast, lung, colorectal and prostate increases with age with the majority (74%) of these cases occurring in those aged over 60 years (Yanick & Ries 2004, DH Cancer Reform Strategy 2007). A further concern is that older people, aged over 75 years, are more likely to present with advanced cancer at diagnosis (ONS 2009). Indeed, the number of over 75's is the most rapidly increasing proportion of the UK population and presents a largely un-researched health care group (ONS 2009).

This increasingly aged population presents a significant demographic challenge for society and health care provision as old age is correlated with health inequality (Allmark *et al* 2010). In response to this challenge, the UK Department of Health developed the National Service Framework (NSF) for Older People (DH 2001). Recommendations in the NSF included that older people should be treated with dignity and respect and advocated 'person-centred care'. In an attempt to provide for and meet the health care needs of the UK's ageing population, the Department of Health launched the 'Dignity in Care Campaign' (DH2006). This has been further acknowledged in the Healthcare Commission's report 'Caring for Dignity' and the UK Government's Joint Committee on Human Rights report 'The Human Rights of Older People on Healthcare' (Healthcare Commission 2007, House of Lords House of Commons Joint Committee on Human Rights 2007). Respect and dignity for all, regardless of age, now comprises one of six core NHS values, which are outlined within the NHS Constitution (DH 2009). This is increasingly important as older people proportionately are the greatest users of health care services in the UK (HES 2010).

Though UK policy initiatives have targeted the health needs of an ageing population, older people have been neglected both in planning and delivery of cancer services with services mainly targeted at a younger adult population. The publication of the National Cancer Survivorship Initiative (NCSI) demonstrated a policy commitment by the UK Government and Macmillan Cancer Support to recognise the specific psychological, physical and social issues resulting from having had cancer and to support research into the needs of all people living

with and beyond cancer (DH 2008a). However, for those with palliative care needs, the long awaited *End of Life Care Strategy* for England has made little mention of older people (DH 2008b). Similarly, the Gold Standards Framework and the Liverpool Care Pathway, which clearly endorsed the importance of adequate assessment and pain relief for cancer, have made scant reference to the needs of older people (Thomas & Free 2006, Ellershaw 2007). Indeed, increasing concerns such as health inequalities and poor provision of care for older people with cancer have been noted in the 2007 Cancer Reform Strategy (DH 2007). Sadly, this was recently reiterated in the findings of the 2011 Ombudsman's Report 'Care and compassion' which raised concerns that older people do not get adequate or appropriate services and identified that older people need better care and care which is suited to their needs (Parliamentary and Health Services Ombudsman 2011). Thus, more needs to be done to identify and address the unmet needs of older people with cancer.

The health care needs of older people are complex and challenging. With increasing age comes increasing risk of all disease, including cancers, suggesting that large numbers of older adults will need cancer treatment. Older people with cancer are more likely to become frail and vulnerable (Mohile *et al* 2009). Also, in older people, the side effects of cancer and its treatment are likely to be compounded because of chronic comorbidities and the natural ageing process (Adams *et al* 2004, Ferlay 2007). Despite the risk of late diagnosis, improvements in the treatment of cancers have resulted in improved rates of survival for older people (Devane 2009). Cancer survivorship, in an increasingly aged population, has important implications for clinical practice, such as the management of multiple co-morbidities including pain (Avis & Deimling 2008:3520). Pain is not confined to those with active cancer. Recent meta-analysis of European data suggests that pain prevalence may occur in one third of cancer survivors (van den Beuken-van Everdingen *et al* 2007). Thus, the effects of the cancer and its treatment may result in chronic health problems, including pain, many years after treatment for the cancer has ended (Alfano & Rowland 2006).

However, the extent and nature of the problem of pain in older people with cancer is largely unexplored (Royal College of Physicians *et al* 2007, Hadjistavropoulos *et al* 2007, IASP 2008). There are many possible contributory factors to this, some of which are considered here. Firstly, the majority of studies of cancer pain have excluded those aged 65 and older (Goudas *et al* 2005, Balducci 2003, Bernabei *et al* 1998, Cleeland 1998). Additionally, older people have largely been absent from cancer and end of life research (Bugeja *et al* 1997, Seymour *et al* 2002, Avis & Deimling 2008, Breivik *et al* 2009). Secondly, older people have been noted to under report their pain experience, particularly if the older person is cognitively impaired

(Bernabei *et al* 1998). Thirdly, the complex and subjective nature of pain experience makes consensus about measuring pain and its effects a considerable challenge for researchers. Many symptoms experienced by those with cancer are also open to interpretation and consideration from more than one level or perspective (Richer & Ezer 2000, Tritter & Calnan 2002). Finally, the presence of existing painful comorbidities and the painful nature of diagnostic procedures, treatment or ongoing management of cancer may be additional and confounding factors to consider (Perkins & Kehlet 2000, Jung *et al* 2003, Maguire *et al* 2006, Burton 2007). Thus, the scale of the current problem of cancer pain and suffering, for older people is likely to be significant.

In the absence of understanding the nature and extent of the problem, management of pain may present a major issue for older people with cancer and their healthcare providers. In a large recent European study (n= 5084) of people of all ages with all types and stages of cancer, older people were noted as receiving suboptimal pain management (Breivik *et al* 2009). In smaller studies, pain has been noted in up to two thirds of older adults with advanced cancer, with many receiving inadequate pain relief (Fineberg *et al* 2006, Zyczkowska *et al* 2007). Furthermore, it has been observed that older people with cancer do not always have access to specialist cancer or palliative services (Cleeland *et al* 1994, Bernabei *et al* 1998, Cleeland 1998, Burt & Raine 2004, Froggatt & Payne 2006, Duncan *et al* 2008). Indeed, older people have access to generic provision of care, which is largely informed by studies of younger adults, and have to fit in with existing services (DH 2007).

Inadequately managed pain is known to have detrimental effects on quality of life and activities of daily living (Portenoy & Lesage 1999, Lin *et al* 2003). Moreover, the individual experience of cancer pain is unique and complex because of its multifactoral nature and because of the potential for association of worsening pain with progression of disease (Turk & Fernandez 1990). Indeed, there may be a popular perception that experiences, such as cancer and pain in old age, are inevitable and thereby, worthy of less resourcing within research and consequently health care provision (Biggs & Powell 2001).

Despite increased prevalence in an ageing population, cancer and its symptoms are significant and under researched issues for older people. Indeed, older people, regardless of physiological or chronological age, need representation in health care research. The ageing population and increasing survivorship of older people with cancer provide challenges, for health researchers and health care providers, in both defining and meeting older people's health care needs.

These challenges include understanding the extent of pain as a problem for older people with

cancer, managing pain and understanding the effects and difficulties of living with cancer and pain. If the effects, on older people, of living with cancer and pain are not understood care cannot be appropriately planned. Thus, the voice of older people needs representation to establish their needs, inform their care and influence the direction of future policy and service provision. The purpose of this study is to listen to the voice of older people with cancer pain and use some of these personal experiences to better inform care and future strategies of inquiry.

5. Plan of the Investigation

5.1. Methodology

Aim:

- To consider how older people construct the experience of cancer pain and how this is informed by expectations and experiences.

Objectives:

- To understand the experience of cancer pain in older people
- To illuminate underlying themes and contexts, that may account for this experience.

The research aim and objectives will be addressed through use of a qualitative research design informed by the principles of phenomenology.

The study will comprise the following stages:

1. Solicited diary of older people who have experienced cancer pain
2. Interview with older people following completion of a solicited diary.

5.2 Design: type of study design and justification

A phenomenological approach is appropriate for the exploration of a subjective experience, such as pain, in the context of living with cancer (Seymour & Clark 1998). Objective pain measures and 'tools' can be considered as creations of natural science which are limited in their ability to capture the whole experience of living with cancer and pain (Herr & Garrand 2001). To understand the experience of cancer pain will draw upon the importance of the personal perspective of the experiencing person rather than the view of the researcher (Polit & Beck 2008). Thus, understanding the experience of cancer pain may be considered as more than the measurement of pain and may be expressed in the concepts of patient centred and holistic care (Nolan *et al* 2004, McCormack 2003, Ellis 2009). Qualitative approaches, such as

phenomenology, may offer a meaningful opportunity to consider the construction of the lived experience (Dilthey 1976). The qualitative methodological framework will ensure that this subjective and potentially sensitive experience is considered with empathy and compassion whilst ensuring a rigorous approach to the data in the application of interpretive phenomenological analysis (IPA) (Smith *et al* 1999).

5.2.1 Methods: The Diary Interview Method

The individual's experience of living with cancer and pain will be best captured through qualitative methods. The diary-interview method is congruent with both phenomenology and 'patient centred care' (Zimmerman & Weider 1977, Milligan *et al* 2005). Diaries are appropriate for collection of data which may inform both quantitative and qualitative research. Furthermore, solicited diaries represent a pragmatic solution to ensuring that the 'voice' of the older person is represented in research (Jacelon & Imperio 2005, Alaszowski 2006:113, Ryan 2006). Their usefulness is established where it is important to capture events and their effects over a defined time period, where memory may be an issue and where context and veracity may be significant concerns (Newton *et al* 2010). Using a diary may also afford the opportunity to reveal things, perhaps thoughts and feelings, and sensitive subjects which might not be easily said to an interviewer (Furness & Garrud 2010). In palliative and cancer care the combined use of diary and interview has been noted as an effective methodology (Richardson & Ream 1996, Sheriliker & Steptoe 2000, Wu & McSweeney 2007, Broom & Tovey 2008, Hermansen-Kobulnicky 2009). Qualitative interviewing, the second method of data collection to be used in this study, is also widely established as a method of exploring the perspectives of service users in cancer and palliative care (Seymour & Clark 1998, Collins *et al* 2010).

There are several possible disadvantages of using a diary interview method. Firstly, there is an implicit assumption that the participant is able and or willing to complete the diary. The use of diaries assumes people's ability to write and that they are sufficiently motivated to keep contributing (Alaszowski 2006:50). Thus, a diary may exclude the cognitively impaired or those unable to write. Furthermore, people may be inconsistent in the data which they record in the diary. This may be because participants change their behaviour due to keeping their diary or because of disinterest over the allocated time. The study will necessarily recruit volunteers and thus, the study will be biased towards those who are literate and willing diary keepers. For those who are willing diary keepers, the personal collection of diaries may further influence their altruistic nature and participation.

The second issue is that, completion of the task may be perceived as a burden (Cook *et al* 2002). Because of the risk of fatigue associated with its completion, the suggested time limit to keeping the diary will be a maximum of 2 weeks. The information to participants will reinforce that the diary is voluntary and remind them that there is no compulsion to complete any or all of the suggested diary days. The time commitment may be a significant issue therefore the diary must be simple and straightforward. Indeed, a free open format to the diary is preferred to a highly structured one to reduce the perceived burden.

Finally, the amount and cost of dealing with the diary data may be prohibitive (Alaszowski 2006). Indeed, the potential cost of this method involving a minimum of two visits per participant will be more than a straightforward interview method. Having an open diary format may produce an unknown and varied quantity of data requiring more time needed to analyse the data. Thus, to accommodate for the variability in each individualised diary an interview guide will be used as a reserve option to inform and prompt the qualitative interviews.

The diary interview method is an approach which may ensure greater quality and accuracy of the individualised data and consequently rich and insightful findings (Ryan 2006). Furthermore, it is anticipated that the solicited diary when followed by an interview may also enhance the validity of the findings (Kenten 2010).

5.3 Analysis

The data analysis will follow the stages of Interpretive Phenomenological Analysis (IPA) identified by Smith & Osborn (2008). The diary and interview with each participant will be considered and analysed individually. Each interview will be transcribed and initially coded into sub themes and clustered, ensuring that the connections draw upon the original words and phrases used by the participant. This will follow an iterative and logical process ensuring that all subthemes are supported with reference to the individual phrase or sentence used. Further, reading and rereading of the transcripts will be used to inform connections and clustering of the subordinate themes into emergent themes and finally superordinate concepts. These findings will be presented as themes, accompanied by subordinate themes and contextual references from the individual's transcript to represent each as an individual case study. This iterative and interpretive approach will be repeated with each participant's diary materials and transcribed interview. It is not intended that data generated should be generalisable to the wider population however, after all interviews and initial analysis is complete any commonly occurring themes between individuals will be considered and analysed using the same IPA stages.

5.4 Setting

The research location will be within the South Yorkshire area for practical reasons of geographical location in proximity to the researcher's place of work (Sheffield) and existing contacts in clinical situations. The Rotherham Hospice and the community palliative care multidisciplinary team (MDT), which is based at Rotherham Hospice, have been approached as potential sources for recruitment. The MDT includes the Palliative Care Consultant and Hospice clinical lead Dr Fiona Hendry, MacMillan services, local GPs and community nurses.

5.5 Participants

Older people, with cancer, who are aged 65 years or older.

5.6 Recruitment of Older people who access community based palliative care services

The Rotherham Palliative Care Service is a specialist multi-professional team, consisting of GPs, Macmillan and District nurses, who meet weekly to support the needs of people referred for palliative care services. The team aims to promote quality of life from the point of diagnosis through all the changing phases of illness. To ensure that there is no breach of the data protection act and that the participants are volunteers thus complying with the tenets of human ethical research the participants will be known to the palliative care team and the researcher will have no prior knowledge of or contact with any participant. Health care professionals from within this team will be asked to identify older people (aged >65) with cancer pain who met the inclusion criteria and send invitation letters, information sheets, study reply form, consent form and a freepost envelope to eligible participants.

The theoretical position of IPA suggests a small sample size because of the detailed analysis which this requires. This is to ensure that the phenomena of the individual experience is adequately illuminated without loss of nuance and subtle meaning (Brocki & Weardon 2006, Baker & Edwards 2012). Thus, with respect to the tenets of phenomenological analysis, the numbers of participants will be limited to a maximum of 15 to ensure adequacy of data (Smith *et al* 1999).

Participants who identify themselves as interested will contact the researcher by returning the study reply form in the stamped addressed envelope provided. Once completed reply forms are received the researcher will contact the potential participants by telephone to describe the study, go through the information sheet with them explaining any points of query and ask if they would agree to take part. The researcher, who is a registered nurse with experience of care of older people and of conducting qualitative interviews will use the telephone conversation as an opportunity to assess the suitability of each participant using the inclusion

and exclusion criteria outlined below in sections 5.6.1 and 5.6.2. An appointment to meet with the researcher will be arranged with those individuals who have verbally agreed to participate in the study. This appointment will take place at the participant's preferred location (their home or other). During this appointment participants will be asked to sign a consent form. A two week 'page a day' diary will be given to each participant at this initial appointment which the participant will be invited to complete (Annex 1). Each participant will be invited to complete the diary and this will be supported by the researcher making a midway telephone prompt.

The second phase involves an interview with each participant. The content of the diary will be used to inform the questions asked at interview with each participant; this will be to afford each participant the opportunity to elaborate on any points raised and discuss others in greater depth. In the absence of sufficient diary data to encourage the discussion, the researcher has developed a question prompt (Annex 2). The interview will take place at a mutually convenient time, at the participant's preferred location approximately 4 weeks after the initial appointment. After completion of data collection all participants will be offered the opportunity to receive a summary of the anonymised analysed findings.

5.6.1 Inclusion Criteria:

- Aged 65 years and above
- Diagnosis of cancer within the last 5 years
- Awareness of Diagnosis
- In receipt of community based specialist palliative care services
- Experience of pain as a symptom of cancer or subsequent treatment
- Living at home, not in institutional care.
- People who have capacity to consent and complete the diary

The above criteria have been informed by the following considerations for purposive sampling of participants. Firstly, the age of recruits has been considered as few studies have considered older people's cancer experiences (Chouliara 2004). Secondly, older people are largely excluded from cancer studies (Breivik *et al* 2009). Thirdly, older people in receipt of specialist palliative care have not been the subject of recent study (Devane 2009). Fourthly, breast, lung, colorectal and prostate incidence is greatest in those aged over 60 years (Yanick & Ries 2004, DH Cancer Reform Strategy 2007). Finally, as less than 5% of older people live in institutional care it would seem appropriate to consider the experiences and needs of the majority of older

people who live in their own homes (CSCI 2006). Using data from older people who are usually resident in their own homes may also provide more natural data in a context where they are more likely to freely express their experiences and concerns. Indeed, home is also the preferred place of care for many older people (CSCI 2006).

5.6.2 Exclusion Criteria

- People who cannot speak or understand English
- People who cannot write
- People who are unable to provide informed consent, or too ill or distressed to take part.

The choice to exclude non-English speakers has been made for pragmatic reasons of time and limited resources. However, the experiences of older people who do not speak English and other minority groups are worthy of separate study (Jiwa 1999). In the thesis this will be acknowledged as a limitation of the present study.

5.7 Withdrawal Procedures

Participants will be free to withdraw at any point in the study without prejudice and will be reminded of this at interview and subsequently.

5.8 Safety Assessment

Lone worker policy- risk assessment and procedure as per Suzy Lamplugh Trust guidance www.suzylamplugh.org

5.9 Project Time line

Stage	Participant Time Commitment	Dates (approx)
Potential participants identified and given information pack and researcher contact details by a member of the Palliative Care MDT or Day Hospice.		Oct-December 2012
Participants reading letter and Information Sheet	30 minutes	Oct-December 2012
Completed reply forms received by researcher		December-January 2012
Researcher telephones potential participant to assess suitability and arrange time and venue for giving diary	15 minutes	January 2012
Explanation of Procedure, written consent and giving a blank diary to complete	30mins	January- February 2013

Completion of diary	0-60 minutes as preferred by participants, per day over 3 weeks	January-February 2013
Telephone Prompt	10mins	January-February 2013
Telephone 30 mins prior to interview to confirm visit	10mins	January-February 2013
Interview participation	45-60 mins	February –August 2013
Data analysis		February- September 2013

6.0 Ethical Issues

The main risk to participants is the possibility of distress or discomfort when discussing a sensitive issue such as cancer pain. Cancer, because of its associations with suffering and reduced life expectancy, can be an emotive and sensitive area for research (Wilkie 1997, Addington Hall 2007, Allmark *et al* 2009). These issues will be addressed by using a sensitive approach to questioning. The participants will be reassured that they do not have to answer any question if it upsets them, by reminding participants that all communications (diaries and interview responses) will be kept confidential. The main risk is of causing emotional distress to the participant. The things that may lead to causing distress are unknown to the researcher. Apparently innocent and innocuous questions about the participant's life and family may give rise to painful emotions and thoughts. If this happens the researcher will respond appropriately as an experienced registered nurse and if needed take advice from the palliative care team. Also, the participants will be advised that if they have concerns, expert counselling services are accessible via the palliative care team or the GP. Furthermore, the researcher is a Registered Nurse and has much experience of dealing with sensitive questioning both from her years working as a pain nurse specialist and more recently as a researcher.

6.2 Ethical Issues of Method

A study which engages with people's experience of cancer relies on having a sensitive, informal and relaxed approach to data collection (McIlpatrick *et al* 2006). Using an in-depth interview, undisturbed in a private non-hospital based location would appear to be the most suitable approach to acquiring data about the cancer pain experience.

However, the process of interviewing the older and potentially vulnerable adult with cancer raises some particular practical and ethical issues (Allmark *et al* 2009). The first consideration is that informed consent may be difficult to obtain if the researcher does not wish to reveal the questions prior to interview, but, the researcher will explain that she is exploring the experience of cancer pain in the initial telephone conversation and reinforce this when giving the diary. Kvale (2007) also suggests that the researcher gives careful consideration to whether the initial question should be the central research question of the study or whether the questioning should be more general so as not to lead the potential responses towards one which the researcher is expecting.

Secondly, the participants' privacy must be safeguarded (Barnes 1992). A hospital or institutional setting may be an unsuitable choice for interview, as maintaining the dignity and privacy of the research participant may be difficult. Access to suitable private and sound proofed rooms where there is no interruption may be an issue (Steeves 2000). This can only be addressed through negotiation with the health care setting; however, the participant may prefer to be interviewed in their own home. If one is to obtain an account of the lived experience and how it affects the life world of the individual an institutional setting might be unsuitable. Moreover, the institutional setting may not provide a relaxed setting suitable for asking questions about the cancer pain experience. The cost of participants travelling, to a venue for interview, could also present an issue. Thus, the pragmatic choice may be to ask the participant if it is convenient, and more appropriate, to interview them in their own home provided the interviewer's safety is not compromised. Furthermore, the participant may wish for a family member to be present, again a pragmatic stance will have to be taken. If the family member remains quietly present then the researcher will have to consider whether the narrative of the conversation is acceptable for inclusion or is compromised by their attendance.

Thirdly, the relationship between researcher and participant may easily become one of nurse and patient rather than researcher and participant, raising the concern of a resulting power difference in the communication which could affect the openness of the conversation (Richards & Elmslie 2000). Kvale (2007:14) suggests that there is a *power asymmetry* in qualitative research interviews. This relates to the nature of the conversation between a researcher, who may be perceived as more knowledgeable and who has initiated the interview. This is not a normal conversation between two equals and the interviewer may guide or manipulate the dialogue towards the expected themes of the experience. The researcher will have to consider how the relationship is introduced, whether as 'stranger',

'researcher' or 'nurse'. Thus, the ability of an experienced registered nurse to make the in-depth interview less hierarchical will be challenging. The researcher is a nurse, with many years experience of working with people with palliative care needs, and therefore will have experience of engaging in empathetic conversations.

Fourthly, there is a risk of resurrecting bad memories which may cause distress. Though it is unlikely that participants would be unaware of their diagnosis, they may not know or may not have accepted their prognosis (Hagerty *et al* 2005). Indeed, the participant may not have acknowledged the severity of the disease and its progression. This could lead to considerable emotional distress and anxiety (Wilkie 1997). If participants are unaware of diagnosis or prognosis then it would be inappropriate to proceed. However, discussion of either diagnosis or prognosis is not envisaged as part of the interview; but, the researcher will have to prepare for this and other possibly uncomfortable questions during the course of the interview. The researcher, a registered nurse, has experience of working in a clinical environment where older people have a variety of diagnoses and prognoses, and has well developed empathy and diplomacy skills to deal professionally with such queries and not cause anxiety. Should any participant appear distressed or express concern about any anxieties raised then contact will be made with the appropriate healthcare team to offer counselling or other psychological support. The researcher acknowledges that part of her training and professional registration enables her and requires her to offer help to the distressed and that there may be a tension in qualitative research between viewing participants as person first and patient second (Ritchie 2009).

Fifthly, interviewing older people who have pain and or fatigue at the time of interview may affect their ability to concentrate and cooperate (Grande & Todd 2000). Moreover, the symptoms and general physical conditions of any participant may worsen unexpectedly. It will be unethical to proceed if the participant feels unwell and unable to participate. Therefore, a pragmatic approach will be taken, prior to each planned interview, as to whether it is appropriate to proceed and the participant will be phoned again to confirm if they are still feeling well enough and wish to be interviewed. Furthermore, if pain is to be discussed as part of the experience of pain there may be an expectation that pain relief will be given or the regime modified. Thus, it is important that as part of the recruitment letter and at the beginning of the interview that the researcher clearly states what the research is for and what it cannot do.

Finally, the length of interview appropriate for older people with cancer is an important practical consideration. The interview will therefore need to be sufficiently short so as not to inconvenience the participants nor cause fatigue or distress (Corbin & Morse 2003). However, the researcher will need enough time to explore the research question in a relaxed and informal way so as to maximise the natural enquiry and quality of described experience. Short but intense interviewing would not produce a natural conversational response. However, the length of the interview will affect the numbers needed to achieve informational redundancy. Thus, considering the potentially vulnerable nature of participants, an optimum interview length would be in the range of 45 to 90 minutes (Corbin & Morse 2003:344).

6.3 Project Site file

A project site file will be maintained at Sheffield Hallam University (SHU) in accordance with SHU requirements ([FREC](#)) to ensure confidentiality of all personal data and to meet the requirements of NHS research ethics.

This site file will include the following:

- Study protocol and approved documentation
- Reports from lay and independent scientific review
- Research Ethics Approval from IRAS and NHS R&D
- Letters of authority
- Participant information
- All study data
- Correspondence
- Other study related literature and documentation
- Consent forms
- Interview recordings

As this is likely to involve NHS patients' data will be stored in a secure format, e.g. encrypted data storage device, at the University for a minimum of 7 years.

6.4 Benefit to participants

It is important to consider whether the potential for benefit will outweigh the risks of harm to any individual (Hopkinson *et al* 2005). Moreover, there may be a desire for people to participate for altruistic reasons, for the greater good or that they wish to 'give something back' (Seymour & Ingleton 1999:68, Peel *et al* 2006). It is hoped that the older people who participate in this study will feel more valued and respected. These older people may also wish

to continue with diary keeping, so as to evidence and reinforce their needs and concerns with their professional and lay carers, as an adjunct to pain assessment tools. Participants will be acknowledged in the resulting thesis and in any publications to acknowledge the effort they have made to participate. However, it is unlikely that the participants in this study will benefit directly.

The research findings may benefit patients with cancer in the future. The findings from this study will inform and enhance, local services ensuring that the voice of older people has representation. This study will also inform future inquiry into the needs of the oldest old with cancer pain living in the community.

7.0 Service users

The North Trent Cancer Network Consumer Research Panel (NTCN CRP) has been consulted to review this protocol, information sheet and consent form.

8.0 Dissemination

The findings from this study will be disseminated to appropriate audiences:

- (1) the local health care trust which has facilitated and participated in this study, including the local policy makers and practitioners who support the planning, governance and delivery of care for older people with cancer.
- (2) Practitioners nationally via professional forums such as the British Pain Society, BSG and the PCRS
- (3) Academics will be informed by publication in appropriate professional peer reviewed journals.
- (4) The wider service-user community will be informed locally through the North Trent Cancer Research Network consumer research panel and other local cancer forums.
- (5) A copy of the thesis will be lodged in Sheffield Hallam University's open-access internet archive SHURA.
- (6) To the participants, a summary.

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Annex 1

Diary Guidance

Guidelines for Diary Keeping (Aide Memoir for Participants)

The date

What happened to make you aware of the pain?

Where were you?

Who else was there?

How did it make you feel?

Did you do anything to deal with the pain?

What did you do and was it effective?

Despite the pain, did you manage to enjoy something today, such as a hobby or leisure activity, social visit, going out?

These questions are only intended as a guide. If there is anything else about this experience which you want to record please write it here.

Please do not worry about handwriting, spelling or grammar. Capturing what you are experiencing and feeling is more important.

The researcher will call to collect the diary at a mutually convenient time.

Annex 2

Interview Schedule & Prompt

Introduction of researcher to participant.

Give information sheet regarding study.

Talk the participant through the information sheet-

- Explanation of purpose of interview
- Outline of timing and structure.

Opportunity to ask questions/ clarify any points from the sheet or about the study.

Reaffirm participants consent to interview and being recorded.

Reinforce participants' right to halt the interview at any point not answer any questions.

Start recording interview.

Reaffirm patient consent and volunteering for interview.

Main Question:

Tell me about your experiences of having cancer and pain ?

Possible prompts:

- What did you feel like....?
- What do you mean by....?
- Tell me more...?
- Can you explain...?
- When did it occur, did anything particular bring it on ?

Offer the opportunity for the participant to ask any questions. Offer the opportunity for the participant to share any additional information by telephone or other means if they want to.

Thank the participant for their contribution and time.

Creswell (1998:124,127)

Annex 3

Lay summary- as sent to the NTCN CRP for consideration

Cancer is a disease of older people and the number of older people in the UK population is anticipated to increase to represent 22% of the adult population by 2031. People with cancer aged over 75 years are most likely to present with advanced cancer at diagnosis and are an underrepresented group in UK studies. Amongst people with cancer, pain is a common and distressing symptom: up to two thirds of people with cancer will experience moderate to severe pain. This increasingly aged population presents a significant demographic challenge for society as older people are known to be disadvantaged in respect of healthcare provision. Though UK policy initiatives have targeted the health needs of an ageing population, older people have been neglected both in planning and delivery of cancer services with services mainly targeted at a younger adult population. The health care needs of older people are complex and challenging. With increasing age comes increasing risk of all disease, including cancers, suggesting that large numbers of older adults will need cancer treatment. Indeed, older people with cancer are more likely to become frail and vulnerable. However, the extent and nature of the problem of pain in older people with cancer is largely unexplored. In the absence of understanding the nature and extent of the problem, management of pain may present a major issue for older people with cancer and their healthcare providers. Inadequately managed pain is known to have detrimental effects on quality of life and activities of daily living.

The purpose of this study is to listen to the voice of older people with cancer pain by use of a diary and interview method and use some of these personal experiences to better inform care and future strategies of inquiry. The findings from this study should inform and enhance local services ensuring that the voice of older people has representation. This study may also inform future inquiry into the needs of the oldest old with cancer pain living in the community.

Annex 4

Glossary of Terms- as advised by the NTCRP

Phenomenology and IPA

Phenomenology is a philosophical stance taken by some researchers which acknowledges the importance of the individuals lived experience of particular phenomena. Phenomenology is also a qualitative approach to research and in practice has several forms. Indeed, phenomenology can be both a philosophical approach to qualitative research and has its own approaches to how data is obtained and analysed. Any data which represents the participants lived experience of phenomena and describes their lived phenomenal experience may be used in a phenomenological study. The phenomenon, in this study, is older people's cancer pain and the type of phenomenological approach to this is one called Interpretive Phenomenological Analysis (IPA) (Smith *et al* 1999). This IPA approach to studying the experiences of people is focused on understanding the participant's perspective on an experience and is particularly suited to establishing participant's health care needs as part of an individualised and holistic approach to health.

Construct

The research question asks 'how do older people *construct* their experiences. Construct in this question refers to the multidimensional nature of the pain experience where pain is influenced by context and may be informed by a variety of expectations, experiences and knowledge through which people live with and express their experiences.

Vulnerable

Vulnerability may occur at any age and is not a chronological term and individual participants may not be vulnerable as defined by the Department of Health⁴⁰ (DH2000). However, when referring to older people in this study they may be vulnerable firstly because they identify themselves as vulnerable and this will be respected. Other factors which may identify an individual as vulnerable include isolation, physical or emotional dependence. For people who have received a diagnosis of cancer the term vulnerability may relate to their experiences of traumatic or adverse emotional events through diagnosis and subsequent treatment.

⁴⁰ "a person aged 18 or over, who is in receipt of or may be in need of community care services, by reason of mental or other disability, age or illness, and who is or may be unable to take care of him or herself, or unable to protect him or herself against significant harm or exploitation" DH (2000) *No Secrets: guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse*. TSO

Older People's Cancer Experience Participant Information Sheet

Invitation to participate in the study

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. So please read this leaflet and talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of this study?

This enquiry is part of a doctoral (PhD) study into older people's experiences of the discomfort of living with cancer. The experience of older people has been neglected in healthcare research about cancer care. This study aims to give a voice to older people's experiences of having and living with the discomfort of cancer.

Why have you been invited to take part?

You have been invited to take part in the study because you are aged 65 or older, been diagnosed with cancer and may have experienced discomfort from the tumour and or the treatment.

Do you have to take part?

Your decision to take part in this study is entirely voluntary. You may refuse to participate or you can withdraw from the study at any time. Your refusal to participate or wish to withdraw will not influence in any way your current or potential future medical care.

Please keep this information leaflet for future reference.

What will you have to do if you agree to take part?

If you agree to take part in the study we may ask you to consider completing a diary about having discomfort or pain and note how this has affected you. You will be interviewed about your experiences of cancer and if you have completed the diary you will be given the chance to discuss what you have written.

What are the possible disadvantages and risks of taking part ?

It is unlikely that you will experience any disadvantage. The interview will involve about an hour of your time. The diary keeping may be time consuming but it is up to you how much or how little you choose to write. Discussion of living with and having cancer may be distressing for you and should you feel distressed then there will be no obligation to continue and you may stop keeping the diary or halt the interview as you wish.

What are the possible benefits of taking part?

It is hoped that you will feel more valued and respected as a result of participation in this study. You may wish to continue with keeping a diary to help inform your carers about your needs and concerns about having cancer. The findings of this study will be used to inform local services and planning of care. More research may be initiated as a result of this study which contributes to the body of knowledge about older people living with cancer.

Will your taking part in this study be kept confidential?

Yes. The information from both the diary and the interview will be strictly confidential and kept in a secure locked place at the University. No information which identifies you will be shared with anyone else.

What will happen to the results of the research study?

The results will be presented to members of the Cancer Consumer Panel who have supported the development of this study and to local policy makers and practitioners who support the planning and delivery of care for older people with cancer. The results will also be presented at conferences and in scientific journals.

What will happen to the results of the research study (cont)?

If you request a copy of the findings of this study, this will be given to you after the study is finished.

The results of this study will also be written up as part of a doctorate (PhD) and be placed in the Sheffield Hallam University learning centre (Library).

Who is sponsoring the study?

The sponsor of this study is Sheffield Hallam University.

Who has reviewed this study?

This study has been reviewed by an independent group of people called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity.

The South Yorkshire NHS Research Ethics Committee (NRES) has looked at this study.

This study has also been considered by the Research Ethics Committee at the Sheffield Hallam University and given a favourable opinion.

This study has been reviewed and given a favourable opinion by the North Trent Cancer Research Network Consumer Panel and the Rotherham Hospice Governance Committee.

What should I do now?

If you think you might like to take part in this study please complete the Study Reply Form which is with this information sheet and return it to me, Margaret Dunham in the FREEPOST envelope provided. You do not need a stamp.

Please feel free to call me with any questions about the study and talk to your family or others about this.

If you have any concerns or need further information here are some contact details:

Principal investigator:

Margaret Dunham m.dunham@shu.ac.uk 0114 225 5937

Alternatively, you can contact my supervisor: Dr Karen Collins
k.collins@shu.ac.uk 0114 225 5732

If you would rather contact an independent person, you can contact Dr Peter Allmark (Chairman Faculty Research Ethics Committee) p.allmark@shu.ac.uk 0114 225 5727

Sheffield Hallam University, Faculty of Health and Wellbeing



Thank you for taking the time to read this information leaflet

Please keep this information leaflet for future reference.

Study reply form – please complete this form and return it in the **PREPAID envelope** if you are happy for the research investigator to contact you

Title of Study: **Older people's cancer experience.**

Name of Researcher: **Margaret Dunham**

**Please
tick the
box**

1. I confirm that I have read and understand the research information sheet for the above study and have had the opportunity to ask questions.

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

3. I understand that the above researcher from Sheffield Hallam University who is working on the project will have access to my contact details.

4. I understand that any data or information used in any publications which arise from this study will be anonymous

5. I understand that all data will be stored securely and is covered by the data protection act.

6. I agree that the researcher can contact me on the telephone number below to arrange to meet to give me the diary and organise as subsequent interview at a time and location to suit me.

Name of Participant

Date

Signature

_____ / / _____

Contact telephone number: _____

Address: _____

Participant Consent Form

Study title: Older People's Cancer Experience

Chief investigator Mrs Margaret M. Dunham

Telephone number 0114 225 5937

Participant Name

	Please read the following statements and put your initials in the box to show that you have read and understood them and that you agree with them	Please initial each box
1	I confirm that I have read and understood the information sheet dated date for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	<input type="text"/>
2	I understand that my involvement in this study is voluntary and that I am free to withdraw at any time, without giving any reason and without my medical care or legal rights being affected.	<input type="text"/>
3	I understand that relevant sections of data collected during the study may be looked at by responsible individuals from the Sponsor, the Research Ethics Committee and from the NHS Trust, where it is relevant to this research.	<input type="text"/>
4	I agree to take part in this study	<input type="text"/>
5	I consent to being interviewed and understand that the interview will be recorded.	<input type="text"/>

To be filled in by the participant
I agree to take part in the above study

Your name Date Signature

To be filled in by the person obtaining consent
I confirm that I have explained the nature, purposes and possible effects of this research study to the person whose name is printed above.

Name of investigator Date Signature

Filing instructions

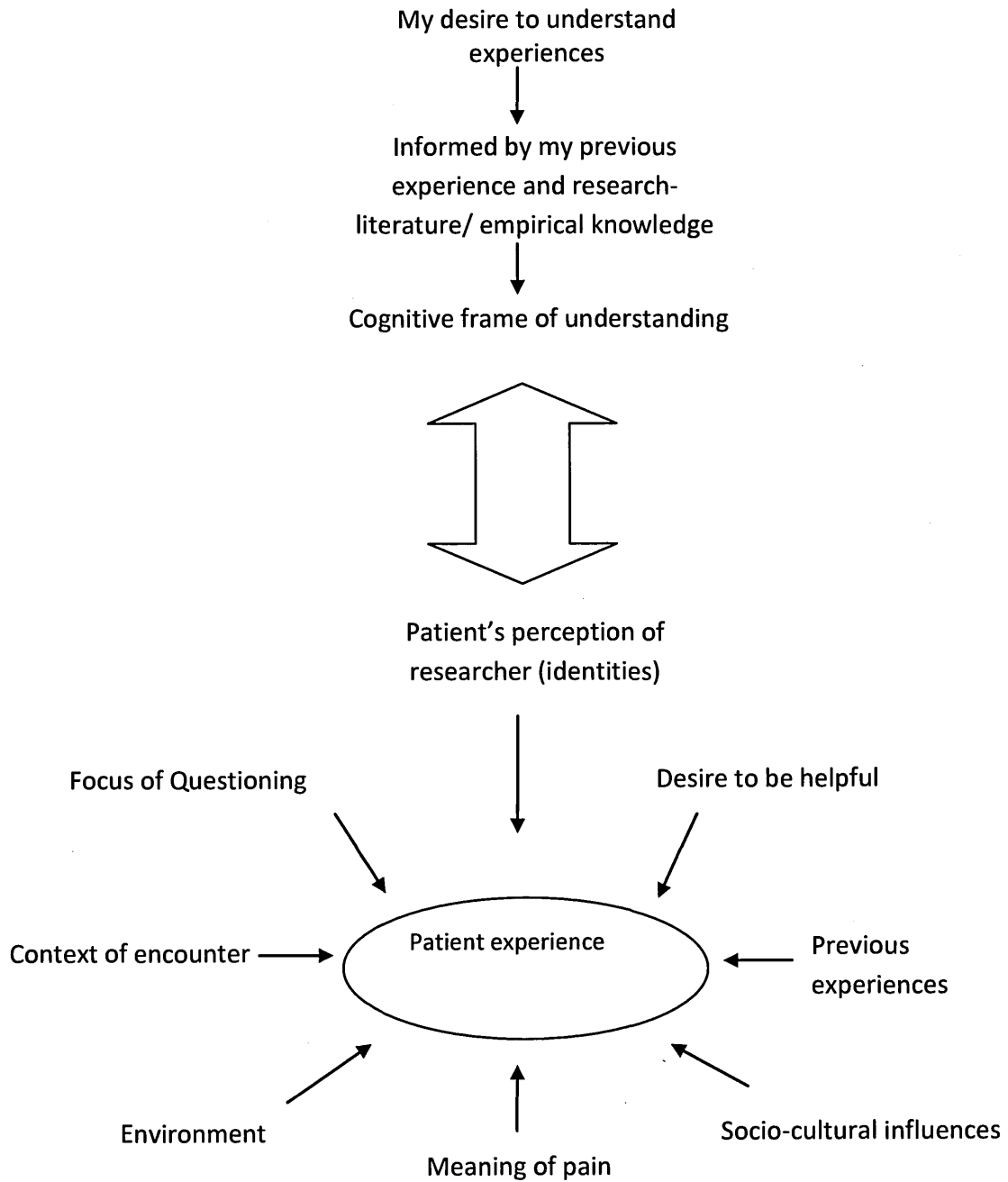
- 1 copy to the participant
- 1 original in the Project or Site file

Appendix I

Conceptual Framework

Informed by types of evidence (McCormack 2002)

- research,
- clinical experience
- patient preference



Appendix J

Extracts from Reflexive Diary June 2013

Meeting and Presenting to the North Trent Cancer Research Network Consumer Panel. 7th June 2013

One of the consumer panel members asked about defining 'end-of-life'. There was no mention of 'end of life' in my presentation but the association with the hospice might have implied this. I need to consider my language use, the connotations and associations of certain words and phrase and particularly whether I have used this term and others appropriately. Am I assuming a 'professional' perspective or understanding of this and ignoring the lay view?

Another question was about transferability to other populations. I stated that I did not think that my work would be generalisable but might 'open a door' (my words) to this unexplored area. There is a clear misunderstanding of the purpose of qualitative research by some and as these are a well informed group I need to ensure that my motives are clear and understandable to the potential lay observer/participant. Also, there are many underrepresented groups who are in need of study and one person defended my stance making reference to this being a PhD study and not a large publicly funded one. Research, particularly small qualitative studies cannot always be representative of the range of potentially disadvantaged groups (Allmark 2004).

Future directions were also discussed-

- Oral histories
- Comparative studies
- Minority groups
- Translation to other languages

After this meeting I reflected on my baggage as a white, middle class, female Christian.

Have I conceptualised old people as vulnerable? What is the foundation for this in the literature?

Extract from reflective diary October 2014

Just finished my interview with **** out at (name of location). I should have expected, as anticipated, that when I switched off the recorder of she would started talking quite animatedly. She talked about more of her friends and her activities and particularly in regard to her expected visit with her son and three-year-old grandchild. The main focus of what she said was about health with independence and stoicism, the other things that she said were about relationships to carers. She didn't want to be a burden to others because she talked of a neighbour who had similarly had pain, cancer related, bit who needed 'virtually everything doing for her' (direct quote from ****). She felt that if she could do things for herself then... Somehow if she needed care she could be depriving others implying that there were always other people worse off than herself. This again reflected a kind of stoicism and concern for the resourcing of care. She had a very pragmatic outlook on life and I have promised to go back and see her just at the hospice because I'll be calling there at the day when she visits, just to tell her how the study is going she wanted to know how things were going and if we make any changes. She also commented that she thought continuing with a similar sort of diary, a more professional one might be useful for her and for other people. We then had a discussion about how it could be used as part of an assessment tool or how it could be used actually in the clinic for future visits or the day centre within the hospice.

Appendix K

Amendment to the Information Previously Given in IRAS

Section A13. Design & Methodology

Participants: Older people, with breast, lung, colorectal or prostate cancer, who are aged 75 years or older.

Changed to

Participants: Older people, with a diagnosis of cancer, who are aged 65 years or older.

Section A17-1. Principal inclusion criteria

Aged 75 years and above

Diagnosis of breast, lung, colorectal or prostate cancer within the last 5 years

Have completed treatment (post active treatment 3 months prior to interview).

Awareness of Diagnosis

In receipt of community based specialist palliative care services

Experience of pain as a symptom of cancer or subsequent treatment

Living at home, not in institutional care.

People who have capacity to consent and complete the diary

Changed to

Aged 65 years and above

Diagnosis of cancer, within the last 5 years.

Awareness of Diagnosis

In receipt of community based specialist palliative care services

Experience of pain as a symptom of cancer or subsequent treatment

Living at home, not in institutional care.

People who have capacity to consent and complete the diary

Section A72

Potentially increase number of sites to include 2 or more hospice palliative care teams as Participant Identification Centres subject to local NHS governance and R&D office approvals.

Amendment to Protocol

5.5 Participants

Older people, with breast, lung, colorectal or prostate cancer, who are aged 75 years or older.

Changed to:

Older people with a cancer diagnosis, who are aged 65 years or older.

5.6.1 Inclusion Criteria:

- Aged 75 years and above
- Diagnosis of breast, lung, colorectal or prostate cancer within the last 5 years
- Have completed treatment (post active treatment 3 months prior to interview).
- Awareness of Diagnosis
- In receipt of community based specialist palliative care services
- Experience of pain as a symptom of cancer or subsequent treatment
- Living at home, not in institutional care.
- People who have capacity to consent and complete the diary

Changed to

- **Aged 65 years and above**
- **Diagnosis of cancer within the last 5 years**
- Awareness of Diagnosis
- In receipt of community based specialist palliative care services
- Experience of pain as a symptom of cancer or subsequent treatment
- Living at home, not in institutional care.
- People who have capacity to consent and complete the diary



Health Research Authority
NRES Committee Yorkshire & The Humber - South Yorkshire

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21 November 2012

Mrs Margaret Dunham
Senior Lecturer
Sheffield Hallam University
Department Of Nursing & Midwifery
Robert Winston Building, 11-15 Broomhall Road
Sheffield
S10 2DR

Dear Mrs Dunham

Study title: Older people's cancer pain experience, a qualitative exploratory study
REC reference: 12/YH/0476

Thank you for your letter of 18 November 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Please note the duplicate 'been' should be removed from the section 'Who has reviewed this study' in the information sheet.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of

A Research Ethics Committee established by the Health Research Authority

the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are compiled with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter	Margaret M Dunham	21 September 2012
Evidence of insurance or indemnity	SHU Liability Insurance letter	31 July 2012
Investigator CV	Margaret Dunham	21 September 2012
Letter of Invitation to participant	Participant reply form v2	21 September 2012
Letter of Invitation to participant	Interview closure form	21 September 2012
Other: Supervisor CV	Dr Karen Collins	
Other: Supervisor CV	Dr Peter Allmark	
Other: Supervisor CV	Professor Whitfield	
Participant Consent Form	5	18 November 2012
Participant Information Sheet	5	18 November 2012
Protocol	3	21 September 2012
REC application		
Referees or other scientific critique report	SHU Faculty Research Ethics Approval Letter	21 August 2012
Response to Request for Further Information		18 November 2012

Letter cont

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/YH/0476

Please quote this number on all correspondence

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

Yours sincerely



**Ms Jo Abbott
Chair**

Email: nrescommittee.yorkandhumber-southyorks@nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Mr Brian Littlejohn
Dr Fiona Hendry, The Rotherham Hospice*

Appendix M Timeline of ethics, revisions & R&D – 18 months of recruitment

March 2012	Registered for PhD at SHU	
14 June 2012	Approached Rotherham Hospice	Dr Fiona Hendry
9 July 2012	DB (CRB) application for Rotherham Hospice	
21 August 2012	Faculty Approval	Peer Review & NTCRN Input
5 September 2012	Rotherham Hospice Trust Approval	Governance agreed for the hospice
8 September 2012	Registration with Rotherham Foundation NHS Trust Research Department.	NHS Research Governance
1 October 2012	Forms for NHS REC	Sent to SY NHS REC & Rotherham R&D team
31 October 2012	Provisional Approval of NHS REC	Advice to attend clinic when the information sheets are given out and be available to answer any questions. Revisions requested to information sheet.
21 November 2012	Full Approval from NHS REC	Letter in Appendix L
10 January 2013	Meeting with hospice staff & MDT at Rotherham	Presenting study and introducing information sheets
4 February 2013	Commenced Recruitment	Rotherham Day Hospice
29 April 2013	Substantial Amendment to NHS REC	Changes as noted in Appendix J above
10 July 2013	First surviving participant	Rotherham
25 July 2013	Local Site File Monitoring	Ethics Audit
26 September 2013	Approached Barnsley Hospice	Diana Gibson
14 October 2013	Approached Barnsley R&D Alliance and SWYT for governance process	Not an NHS hospice so no NHS approvals needed but separate DB checks needed
10 December 2013	Approached Doncaster Hospice (RDASH)	Matron Helen Thompson, access subject to having a Research Passport
20 January 2014	DBS (CRB) for Barnsley	
24 January 2014	Commenced Recruitment	Barnsley Day Hospice
9 February 2014	Research Passport	To access the Doncaster Hospice
21 March 2014	Minor Amendment 1 IRAS Project ID: 109301	Request to remove the word pain from the recruitment information and use the word 'discomfort' instead.
26 March 2014	Notice of Minor Amendment sent to Rotherham	
7 April 2014	Notice of Minor Amendment sent to Barnsley Hospice	
21 May 2014	Approval from Doncaster Clinical Research	NHS research governance
24 May 2014	Commenced Recruitment	Doncaster, St John's Day Hospice

Detailed timeline of recruitment

	Jan 13	Feb 13	Mar 13	April 13	May 13	June 13	July 13	Aug 13	Sept 13	Oct 13	Nov 13	Dec 13	Jan 14	Feb 14	Mar 14	April 14	May 14	June 14	July 14	
Recruitment start & finish																				
Start of recruitment at hospice 1																				
End of recruitment at hospice 1																				
Start of recruitment at hospice 2																				
End of recruitment at hospice 2																				
Start of recruitment at hospice 3																				
End of recruitment at hospice 3																				