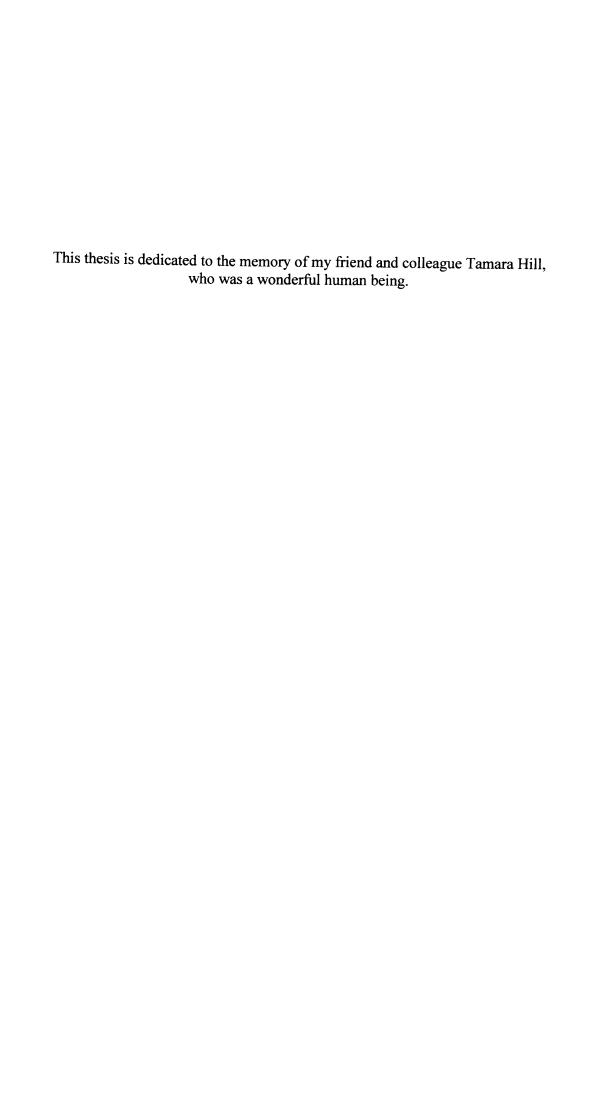# A Study to Explore the Experiences of Advance Care Planning Amongst Family Caregivers of People with Advanced Dementia

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This thesis is dedicated to the memory of my friend and colleague Tamara Hill, who was a wonderful human being.

Acknowledgements

Abstract

A study to explore the experiences of Advance Care Planning amongst family caregivers of people with advanced dementia.

Aim

The purpose of this study was to gain an understanding of Advance Care Planning (ACP) process and experiences from the perspectives of family caregivers as proxy decision makers for a relative with advanced dementia at the end of life.

Methods

The study involved family caregiver experiences of Advance Care Planning within a specialist dementia unit. A qualitative approach using single cases (close family relatives) was chosen for the study. Data were recorded using semi structured interviews from a self selecting convenience sample of twelve family relatives of residents with advanced dementia in a long term care setting. All respondents had been involved in proxy decision making relating to the care and treatment of their relative with advanced dementia. Data were analysed using content analysis.

Results

The family caregiver experiences of Advance Care Planning were numerous and complex. Study participants described Advance Care Planning as a distressing but necessary activity.

Study participants were able to give a good explanation of what was discussed during the completion of the Advance Care Plan. This included management of pain, medical interventions and treatments and also nutrition and hydration needs. A composite case was developed and highlighted several factors that can impact upon the success or failure of Advance Care Planning discussions with family caregivers. This included: adequate education around Advance Care Planning and more information on dementia for families.

Conclusions

Advance Care Planning is a relevant and useful activity to undertake with family caregivers. The value of using Advance Care Planning for the family caregiver allowed the best care for their relative to ensure a dignified death within the care home setting was paramount. However the ethical burden 'to do the right thing' can contribute to the already distressed family caregivers and should therefore be supported by experienced and educated health professionals.

Contents

Chapter Four: Findings

List of Abbreviations

ACP	Advance Care Planning
CQC	Care Quality Commission
DH	Department of Health
EAPC	European Association for Palliative Care
EoLC	End of Life Care
GSF	Gold Standards Framework
LCP	Liverpool Care of the Dying Pathway
LTC	Long Term Care
MCCN	Merseyside and Cheshire Cancer Network
NAO	National Audit Office
NCHSPCS	National Council for Hospices and Specialist Palliative Care Services
NCPC	National Council for Palliative Care
NHS	National Health Service
NICE	National Institute of Health and Clinical Excellence
NPSA	National Patient Safety Agency
NRES	National Research Ethics Service
ONS	Office of National Statistics
PCT	Primary Care Trust
PPC	Preferred Place of Care
WHO	World Health Organisation

Chapter 1: Introduction

1. Introduction

This thesis describes the use of advance care planning (ACP), from the perspective of the family caregivers of people with advanced dementia who were at the end of life and the professional care staff who facilitate these discussions. This included their interpretation, observation and the experience of the ACP process. This thesis adds to the existing developing body of knowledge which identified the appropriate responses to the end of life care for people with dementia and identified the experience of family caregivers when asked to make difficult decisions, which at present is under-reported and not well researched. The definition of 'family caregiver' as used in this study refers to the immediate family member (husband, wife, son, daughter, brother and niece) who was identified as being the 'next of kin' and who also had been appointed 'Lasting Power of Attorney'. A Lasting Power of Attorney is a legal document. It allows someone to act as an 'attorney' to make decisions on behalf of someone when they lack the mental capacity to do so in relation to their financial affairs and/ or personal welfare. A Lasting Power of Attorney cannot be used until it is registered with the Office of the Public Guardian (Barber, *et al.* 2012; HM Government, 2012).

All respondents in this study were either close family members or part of the extended family either previously living with the person with dementia or in a supportive capacity prior to entering the long term care setting. All had been involved in proxy decision making. This chapter includes a critique of the relevant policies and research literature to set the context of the study and its justification. This includes the current challenges to existing service provision for older people, and

in particular those with advanced dementia, who are at the end of life. This chapter concludes with a summary of the thesis outline and organisation.

1.1 Death and Dying

People prepare and experience death in different ways and with different meaning. Death is an event for the dying person (Woods, 2007) and is likely to cause great anxiety as people consider the inevitability of their mortality. Advanced medical technologies and interventions together with improvements in social and working conditions, have increased the length of life for most people (Gomes, *et al.* 2012; Bond, *et al.* 2007). It is anticipated that 25% of the UK population will be over 65 years of age by 2050 (World Health Organisation, (WHO) 2011). As a result of longevity and the medicalisation of death and dying we are less likely to be routinely exposed to dying as in previous generations (Sandman, 2005). A consequence of this is that death is a taboo subject and not something routinely discussed. Concerned by this, the National Council for Palliative Care (NCPC) launched a campaign in 2009 called 'Dying Matters' (NCPC, 2012). The intention of this campaign was, and is, to promote public awareness of dying, death and bereavement by encouraging people to talk more openly about their end of life care wishes (NCPC, 2012). However, death is likely to cause great anxiety as our worst fears provoke the imagination of painful deaths, frailty and bodily decay (Woods, 2007). When death is exposed to us we are reminded of our own mortality and this also has the potential to increase our own death anxiety (Routledge and Juhl, 2010).

Palliative care is now recognised as an intervention that has the potential to contrive conditions under which we can achieve a meaningful and dignified death, and also to

reduce some fears about death and dying (WHO, 2011). Control over the quality of our own dying and death is an essential part of palliative care, but to what extent we are permitted to exercise this control is a controversial and ongoing issue (Gomes, *et al.* 2011a). Despite the majority of people in the United Kingdom (UK) expressing a wish to die at home, most people still die in hospitals (Gomes, *et al.* 2011b). However in recent years there has been a general move towards offering generalist palliative care in care settings such as care homes, primary care and prisons in which generalist staff are supported by palliative care specialists (WHO, 2011). Gomes, *et al.* (2012) report that home deaths have increased for the first time since 1974 amongst people over the age of 85 years, suggesting palliative care interventions in generalist care settings may be having some impact. This is an encouraging sign but unfortunately there remains evidence that the number and scope of palliative care services, particularly for non cancer life limiting illness, varies across the UK (WHO, 2011; Gomes, *et al* 2011b).

As a registered nurse previously employed on an acute medical ward for people aged 65 years and over (within a large District General Hospital in the 1990s), I had ample opportunity to witness the death and dying of older people in a variety of circumstances. Generally non cancer patients were often not diagnosed as dying until almost the very last hour as medical staff heroically attempted to keep the person alive. However this almost 'last minute diagnosis' did not allow for adequate palliative or terminal care to be initiated and patients often had unrelieved pain and were subject to distressing interventions and investigations. Even if several signs can suggest that the patient is dying, decisions about withholding or withdrawing treatment can be difficult for health professionals as they consider the consequences

of hastening the patient's death (withdrawing/withholding active treatment) or prolonging suffering which may impact on the goal of a peaceful death (Hov, *et al.* 2011).

Although there has been attention for the need to improve access to palliative care for all people with chronic life limiting conditions, there is sufficient evidence to suggest that there are obstacles and challenges to making this a reality, particularly for older people, which this chapter will explore.

1.2 Ageing Society, Policy Context

A decline in fertility, combined with improvements in social conditions and medical technologies and interventions, has contributed to the increase in life expectancy within most Western countries, including the UK (Phillips, *et al.* 2010; Bond, *et al.* 2007). It is predicted that by 2050, in the developed regions of the world, a third of the population will be aged 60 years or over (WHO, 2011; Peace, *et al.* 2007). Despite longevity being viewed as a success, perceptions of ageing are often presented as a threat to national and global economies, which is often expressed as anxieties concerning the financial burden on succeeding generations (Phillipson and Baars, 2007). Ageing is often associated with progressive loss of function or adaptability of an individual which includes a growing risk of age related disease (Phillips, *et al.* 2010; Kirkwood, 1999) and which eventually results in death (Grundy, 2006).

Modern consumer cultures have a preoccupation with youth, beauty and energy (Bond and Cabrero, 2007). An enduring stereotype of ageing individuals and

populations is the image of physical and mental decline which leads to eventual disability and dependency (Bond, *et al.* 2007). This negative stereotype is often represented in the media and embedded in popular culture and displays ageing bodies as ugly and in a state of deterioration (Bond and Cabrero, 2007; Westerhoff and Tulle, 2007; Minichiello and Coulson, 2005). The consequences for an ageing population are therefore often referred to in terms of the increased health and social care needs of these groups and a preoccupation with the pathophysiology of an ageing body. This view underpins ageism and can influence the perceptions of normal ageing, as age in itself does not create dependency (Alcock, 2008).

Ageing is a complex multidimensional phenomenon and it is a fact that the ageing body is more likely to display physical and mental limitations in varying degrees as a result of genetics, lifestyle, occupation and socio-economic status (Phillips, *et al.* 2010). There is likely to be a population increase within the oldest cohorts (Grundy, 2006; Bernard and Phillips, 2000) which may also lead to greater diversity amongst the very old as a result of the variations in intrinsic and extrinsic factors. Over the last 30 years the UK has seen a rise in the number of people reaching 100 years old. In 1980 2,500 people were 100 years old or over; this increased to 12,500 in 2010 (ONS, 2012). The Office of National Statistics (ONS) projects that the number of centenarians will rise to 160,000 by 2040 (ONS, 2012).

Current cohorts, particularly those born in the 1930s and 40s are more likely to consume a disproportionate share of the health resources (Blank and Burau, 2010; Baggott, 2004). These cohorts are more likely to have experienced poorer social and working conditions which are now known to influence the experience of ageing and

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the susceptibility to degenerative decline and illness (Peace, *et al.* 2007; Grundy, 2006). This diversity of the population will be reflected in various levels of frailty and vulnerability as a result of chronic physical and mental health conditions (Peace, *et al.* 2007).

Historically, less attention has been given to the importance for individuals to prepare for a healthy old age. Yet sufficient attention to interventions to meet the physical and psychological challenges of an ageing body can have a significant impact on the quality of life of individuals. It is important that care provision is sufficient so that the older person has access to acute care, rehabilitation services, and the provision of long term help and support (Grundy, 2006) as required.

Ageism within the National Health Service (NHS) can impact on older people's access to essential treatment, having their symptoms fully investigated and they are less likely to be referred for specialist services for example, palliative care (British Geriatric Society (BGS), 2009). Peace, *et al.* (2007) suggest that how older people are treated within the health and social care system is the ultimate level of ageism which leads to many people facing end of life within institutionalised settings.

1.2.1 Health and Social Care Provision

Health care and social care in Britain is described as a mixed economy as some is provided by private and voluntary sectors, but most is funded through public taxation which pays for the National Health Service (NHS) (Hallam, 2011). Successive governments within the UK have been criticised over the attention that older age groups have received in terms of access to acute services, coordination of

rehabilitation services and the community care support (Baggott, 2004). Older people

are more likely to use acute services, are hospitalised twice as often, have longer stays

in hospital and be readmitted (Blank and Burau, 2010) more than younger people.

The NHS and Community Care Act 1990 (DH, 1990) changed the face of British

welfare for older people most clearly in the increase in privatisation and rationing

(Blakemore and Griggs, 2007; Komaromy, et al. 2000; Bernard and Phillips, 2000).

This was most noticeable through the closure of long term care wards (Ham, 2004),

the expansion in voluntary and private sector provision in residential and care homes

and the 'emergence of care in the community' (Innes, 2002:483).

Concerns about increased public expenditure, standards of care, limited funding and

challenges of meeting patient expectations prompted a programme of modernisation

(DH, 2006a). The White Paper 'Your health, your care, your say' (DH, 2006a) set

out a scheme to improve community health and social care services for everyone. It

suggested that improved access to choice of care environment and improved

communication amongst health professionals and older people should enhance service

provision. This 'new professionalism', according to Taylor and Hawley (2010:153)

amongst health and care professions concentrates on establishing partnerships

between the public and professionals in order to enable patients to be active

participants and contributors in their own care (Irvine, 2001).

The National Service Framework (NSF) for Older People set out a strategy for the

provision of fair, high quality, integrated health and social care services (DH, 2001).

A progress report from the Health Services Commissioner (DH, 2003a) on the NSF

progress suggested that the NHS failed to meet its obligations to provide continuing

care to older people. This suggests that the needs of some of the most vulnerable people are not being met (Alcock, 2008).

The Wanless Review 'Securing Good Social Care for Older People: Taking the Long Term View' (Kings Fund, 2006), suggested that despite spending considerable sums of public monies there was very little information on the quality of the care experience for older people which included promoting choice, independence and prevention (Kings Fund, 2006). Criticisms over complicated assessment arrangements and funding of long term care, particularly with the contribution required from the older person have been, and remain, the subject of much debate (Social Care Institute for Excellence (SCIE), 2012; Dilnot Commission Report, 2011; Blakemore and Griggs, 2007).

There are currently 4,608 care homes (with nursing) in England which mainly provide care for older people and people with dementia (Care Quality Commission (CQC) 2011a). It is reported that 45% of care home places are occupied by people who are self funding rather than being paid for by the state (CQC, 2011a). The experience of older people in institutionalised care has often been associated with negative perceptions of ageing. Hockley and Clark (2002) suggest that due to their mental and physical frailty, residents in a care home are often viewed as being vulnerable and powerless with the presence of death and dying always imminent. The CQC is an independent regulator of health and adult social care services in England and its role is to make sure that the care provided in care homes meets government standards of quality and safety. Over recent years there have been some concerns over the

standards of care in some care homes (CQC, 2011a) which includes the safeguarding of vulnerable people.

It is difficult to predict the impact of the ageing population on health care costs, but at present it is based on the assumption that more people will survive to the stage at which they will incur high care costs (Alcock, 2008; Bond, *et al.* 2007; Baggot, 2004). Minichiello and Coulson (2005) refer to this as a 'spoiled identity' and suggest that older people may not tolerate this treatment much longer as they become a strengthening political force representing a larger percentage of society.

1.3 Palliative Care

Dying is characterised by the last period of life just before we die and is often associated with a causal chain of events leading up to and causing death (Sandman, 2005). The notion of dying resulting in a good death plays an important role in palliative care but dying is a complex phenomenon as it involves physical, emotional, psychological and social complexities (Woods, 2007).

The disease trajectory of the patient's dying 'career' described by Morrall (2009) is mapped by doctors and nurses on what they believe to be the normal pattern of people with similar disease or illness and this is influential in the care that people are prescribed. Earlier work by Friedson (1970) and Zola (1972) drew attention to how the medical profession claims jurisdiction over the label of illness, irrespective of its ability to deal with it effectively. Glaser and Strauss's (1965) study of the social organisation of dying and death in hospitals identified the 'career pathway' of the

dying person and suggested that dying people enter social phases or critical junctures in the journey from diagnosis to death.

Concepts of a good death are often described in terms of comfort, peaceful, pain free, dignified, autonomous, and free from distress and suffering (Higgins, 2010; Costello, 2004). Bad deaths are associated with poor management, stress, uncontrolled pain and other bodily disintegration, poor communication, organisational and structural constraints (rules and inflexible routines) and indifference by nursing staff and doctors (Woods, 2007; Sandman, 2005; Costello, 2004). Kellehear (2011:25) states that 'the ultimate answer' (to a good death) 'cannot be divorced from the question of what societies believe constitutes a good death' and 'what it means to die well'. However this is repressed due to the reluctance to discuss death and dying as routine subjects within society which adds to the difficulties of seeing dying as part of living (Rumbold, 2011). Mason *et al.* (2011) believe this requires confronting deeply held social taboos and it will take time to encourage people to talk more openly about death and dying.

Palliative care is a philosophy of care for the dying person (Baldwin, 2011) and in developed countries originally focused on the needs of people with cancer (Parker and Froggatt, 2011). Palliative care according to the WHO (2002:1) 'improves the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement' (WHO, 2011; Millington and Potts, 2009; WHO, 2002). Palliative care is viewed as an active process with measureable outcomes (Addington-Hall and O'Callaghan, 2009; Grande, 2009; Woods, 2007).

Dame Cicely Saunders was the founder of St Christopher's Hospice in 1967 and taught the concepts of 'total pain' which addresses the issues of physical, mental, social and spiritual elements to pain and distress and is well established in palliative care (WHO, 2011; Milligan and Potts 2009). Since 1967, the modern hospice movement and palliative care has gathered momentum and the numbers of specialist palliative care services, physicians and nurses have continually increased across the UK and Europe (WHO, 2011; Baldwin, 2011; European Association for Palliative Care (EACP), 2007).

In reality there is no guaranteed access to palliative care within the UK and NHS and access is further restricted when patients are subject to ageist attitudes (WHO, 2011; Milligan and Potts, 2009). This suggests that although death and dying remain medicalised events they could also be subjected to the attitudes and biases of doctors and nurses and their perception or interest in the primary disease (Gott, *et al.* 2011).

This 'hospice' model of care has been adapted to be used for people with longer periods of illness and unpredictable disease trajectories, to support the person through the journey of a terminal illness (Baldwin, 2011; Sutherland and Stevens, 2008). In 2004 the National Council for Hospices and Specialist Palliative Care Services (NCHSPCS) became the National Council for Palliative Care (NCPC) which emphasised the need to manage the needs of terminally ill people wherever they happen to be (Woods, 2007). The NCPC in 2009 launched the 'Dying Matters Campaign' to raise public awareness and debate on issues of death, dying and

bereavement and promote a 'national conversation' to encourage people to talk more openly about death and dying (NCPC, 2012).

Palliative care development acknowledges the role of the multi-professional team members, the expansion into non cancer areas and the 'hidden' aspects of service provision including the visits and contacts with carers (Jack, *et al.* 2009:84). Gott and Ingleton (2011) describe palliative care as a scarce resource and one for which dying people have to compete. Professional 'gatekeepers' make decisions about who is referred to specialist palliative care services which according to Gott and Ingleton (2011) is often made without an understanding of who can, and should, benefit.

More recently there has been a recognition that older people with chronic, non cancer conditions, can benefit from a palliative care approach, but are more likely to be disadvantaged in access. A report in the UK by the National Confidential Enquiry into Patient Outcome and Death (NCEPOD), (2009) identified that the majority of people who die in acute hospitals are over the age of 75 and that 40% were inappropriately admitted to hospital to die. This risk of hospital admission is suggested by Parker and Froggatt (2011) to be a result of inequitable access to specialist palliative care services for older people and a failure to address the complex needs of older people with chronic diseases.

A report by the Kings Fund (2010) which identified challenges to the National End of Life Care Strategy (DH, 2008) included a remaining reluctance to discuss death and dying in British society, the ageing of the population and the demand for services, and the current restrictions on resources which are likely to be in place for several years.

The National Council for Palliative Care (NCPC, 2010b) reported that despite initial funding being made available to Primary Care Trusts (PCT), 35% of them were unable to identify a specific amount they had allocated to end of life care in 2009/2010. The NCPC suggests that greater transparency is required on how PCTs are allocating end of life expenditure.

1.3.1 Palliative Care in Care Homes

The resident population in care homes has become increasingly frail with multiple co-morbidities (Froggatt, *et al.* 2011). In the UK, 20% of deaths in people over 65 years occur in care homes (ONS, 2012; DH, 2008). Death and dying in care homes requires access to specialised care, equipment and support for practical caring needs such as physical, emotional and psychological of both patient and caregiver (Froggatt, *et al.* 2011; Stewart, *et al.* 2011; Costello, 2004).

Education and skills development about palliative care is considered to be central to improving end of life care for people dying in care homes (Peace and Katz, 2003) and to ensure that evidence base and evaluation of interventions include appropriate measurement of outcomes and practice change (Addington-Hall and O'Callaghan, 2009; Grande, 2009). It is not always easy to apply palliative care principles in care homes due to staff turnover, lack of resources and the training and educational opportunities open to nursing and care staff (Froggatt, *et al* 2011; Hov, *et al.* 2011; van der Steen, *et al.* 2009a; Di Giulio, *et al.* 2008; Costello, 2004). Hov, *et al.* (2011) identified additional obstacles for providing palliative care in care homes which included a lack of cooperation between generalist and specialist practitioners and the professional strength and power of nurses to provide the care they want.

Ageism for many older people is compounded by also having to face end of life care within institutionalised settings, with a loss of personal identify and self worth (Peace *et al.* 2007; Hockley and Clark, 2002) suggesting an urgent need for specialist education and training relevant to older people in care home settings (Komaromy, *et al.* 2000).

The National End of Life Care Strategy (DH, 2008) supports a reduction in the emergency transfers from care homes to hospitals in the last weeks of life particularly when residents have expressed a wish to die in the care home (Baldwin, 2011). This has been developed further by the NHS Northwest End of Life Care Programme (2011) Six Steps to Success Programme for Care Homes (NHS NW EoLC, 2011) which guides and facilitates the delivery of palliative care principles in care homes across the north west of England.

1.3.2 Euthanasia.

The current debate on euthanasia and assisted suicide within the UK is worthy of acknowledgement as it relates significantly to the perception of good palliative care and how advanced directives might be used by health professionals in the future (Baldwin, 2011).

Euthanasia is from the Greek works 'eu' and 'thanatus' and means a 'good death' (Heyes-Moore, 2009). Today euthanasia is associated with the intentional killing of one person by another, usually to relieve suffering as a result of extreme distress or pain. Morrall (2009) suggests this is possible through the removal of treatment or

food or the administration of certain types and dosages of medication that may hasten or induce death which could be considered legal, illegal or unethical.

The law as it stands declares that voluntary, involuntary, active euthanasia and assisted suicide are illegal acts in the United Kingdom (UK) (Woods, 2007; Keown, 2002). However it is considered to be ethical and legal to stop treatment that is no longer working and it is acceptable to give treatments to decrease suffering even when a secondary, but not intended effect, might be to shorten life, known as the ethical principle of double effect (Heyes-Moore, 2009; Woods, 2007).

Many people favour legalisation of voluntary euthanasia for reasons which are usually associated with compassion and autonomy and believe this will end human suffering (Keown, 2002). Advocates for assisted suicide often attempt to predict their own best interests in future conditions in which they have no familiarity (Woods, 2007). Motivations for assisted suicide and euthanasia include fear of unbearable suffering, fear of a prolonged suffering, loss of control, spiritual distress, a considered choice 'just in case', prevention of distress to family, lack of state support and help, and diminishing personal resources within ageing societies. It is unfortunate that these issues are of real fear in an affluent society. People do not have to have witnessed an agonising or protracted death for it to be anticipated for their own death.

One of the major obstacles for such a change in the law is that there are insufficient proposals on the safeguarding of vulnerable people (Keown, 2002). It could be argued that if there was sufficient support and access to palliative care, educated and

skilled professionals and investment in new technologies and equipment, this debate may not needed with such regularity.

1.4 Dementia: A Challenge to an Ageing Society

It is estimated that there are currently 820,000 people in the United Kingdom (UK) diagnosed with dementia with an annual cost of £23 billion (Alzheimer's Research Trust, 2010). Although dementia is a disease predominantly associated with later life, there are approximately 15,000 people under the age of 65 diagnosed with dementia in the UK (DH, 2011a). It is also suggested that only one third of people with dementia are formally diagnosed and that many people miss out on early intervention and specialist care (NAO, 2010).

Bond and Cabrero (2007:305) suggested that 'being demented in one of the most negative stereotypes of old age and one that is increasingly in the public eye because of increasing prevalence in the community'. Dementia and dementia care have historically occupied a neglected position on the political agenda in terms of care and research (Innes, 2002; National Audit Office (NAO), 2007) resulting in poor diagnosis and a lack of interest amongst physicians despite some coverage in the National Service Framework for Older People (NAO, 2007; DH, 2001). It is an incurable progressive condition (Mitchell, *et al.* 2004a, 2004b) but is difficult to research prior to death and has often been attributed to natural ageing and not requiring specialised care or treatment (Stieber-Roger, 2006).

Dementia is the term used to describe the symptoms that occur when the brain is affected by certain specific diseases and conditions (Smith and McKenzie, 2011).

Dementia is described as an acquired decline in a range of cognitive abilities (memory, learning, orientation and attention) and intellectual skills (abstraction, judgement, comprehension, language and calculation) accompanied by alterations in personality and behaviour which impair daily functioning social skills and emotional control (Phillips, *et al.* 2010). The most common types are Alzheimer's disease, vascular dementia and Lewy Body Dementia (Sabbagh, *et al.* 2011; Smith and McKenzie, 2011).

Dementia has an unpredictable disease trajectory (DH, 2009a, Mitchell, 2004b, 2004c) it often starts gradually and a typical trajectory can last over several years (Phillips, *et al.* 2010). Mild dementia suggests the person can still manage independently; moderate dementia is when some support is needed to perform tasks; and severe dementia is when continual help and support is necessary (Phillips, *et al.* 2010). Survival rates for people with dementia are dependent on the age at which the disease is first diagnosed and can range from 1.9 years to 6.7 years (Rait, *et al.* 2010). Most people with dementia also have at least one other co-morbidity (NAO, 2007) and often present with complex physical and psychological needs particularly in the advanced stage of the disease (Sampson. *et al.* 2008). In the advanced stage of the disease a person with dementia is at a higher risk for hospitalisation due to an increased susceptibility to recurrent urinary tract infections as bladder function diminishes, pneumonia caused by aspiration as the swallowing mechanism declines and hip fracture as a result of falling due to the diminishing capacity of brain function (Lindstrom, *et al.* 2011b).

Advanced dementia is commonly described as a 'living death' (Downs, 2011). This 'rising tide' of the burden of older people is further perpetuated through the image of people with dementia which is a distressing condition worse than death and that additional resources will not add any value or quality (Innes, 2002). Hughes and Baldwin (2006) suggested that there is a presumption that quality of life is poor but in reality it is possible that the quality of care is poor and that a person might be denied treatment because they are receiving poor care.

The emotional impact of a dementia diagnosis has been underestimated and a better understanding is needed to support people with dementia and their family caregivers (Aminzadeh, *et al* 2007). Family caregivers often take on new roles of responsibility, supervision and decision making early in the disease which is balanced with feelings of increased protectiveness and tenderness (Adams, 2006). It is estimated that twentyfive million of the UK population have a close friend or family member with dementia (Alzheimer's Research Trust, 2010) and that unpaid family caregivers (mainly female) save the UK economy £5.4 billion per year (NAO, 2007).

Although people with dementia and their family caregivers' needs have been acknowledged in the Department of Health National Dementia Strategy (2009a) it is also recognised that their needs have not been fully resourced nor planned for (DH, 2009a). Serious concerns have been identified regarding the inadequacies of knowledge and skills required to meet the needs of this group of people (Alzheimer's Society, 2012).

The National Dementia Strategy, published in 2009, acknowledged a lack of appropriate research, care and treatment and called for a 'transformation' in the quality of care provided for people with dementia and their family caregivers (DH, 2009a). Dementia currently costs the NHS and social care services around £8.2 billion a year (NAO, 2010). Within the 'National Dementia Strategy' it is suggested that this 'state of affairs has not been planned for, either through commissioning services or through workforce planning' (DH, 2009a:57). In a report from the NAO (2010) the relevant government departments were accused of not matching their commitment with a vigorous approach to implement the strategy and that current services do not provide value for money. The coalition government published a revised implementation plan in 2010 which identified the priorities for policy development to improve outcomes for people with dementia and their carers (DH, 2011c). This included accelerating the pace of improvement in dementia care, developing specific measureable indicators across health and social care, and developing a 'National Dementia Declaration' to support local delivery and local accountability. However the NAO (2010) suggested that this will require the release and availability of £1.8 billion of savings from the acute hospital and long-term care sectors to fund early interventions and care in the community.

The Prime Minister, (in post at the conclusion of this thesis) David Cameron, has publicly acknowledged that 'people with dementia and their carers still face a lack of understanding from public services, business and society as a whole' (DH, 2012:3). Improvements in services have been identified to improve the standards of care and service provision by 2015. These improvements include, driving improvements in

health and care, creating 'dementia friendly communities' that understand how to help and better research (DH, 2012).

In recent years there has been an increased interest in the prevalence and experience of living with dementia for patients and families (Peace, *et al.* 2007). Bartlett and O'Connor (2010) suggest that the medicalisation of dementia has two important benefits; it generates scientific interest and research, and has led to a clearer recognition of the family's role in providing care. The negative consequences of medicalisation suggest that the focus is on the disease of dementia and the focus on the physical and mental deficits of the 'demented' (Bartlett and O'Connor, 2010).

Dementia is also a major reason why a person may receive institutionalised care (Coulson, *et al.* 2005), and approximately one third of people with dementia live in a care home (NAO, 2007) and at least two-thirds of all people living in care homes have a form of dementia (Alzheimer's Society, 2012; DH, 2009a). Approximately 208,000 people with dementia live in care homes in which the quality of service varies (CQC, 2010). In 2008 a report by the then Commission for Social Care and Inspection (CSCI) (now Care Quality Commission (CQC)) suggested that many care homes struggle to provide adequate or specialist care to people with dementia and even those care homes which are identified as 'specialist dementia units' did not guarantee quality care (CSCI, 2008). However despite the attention and reports from the regulators, the CQC in 2010 suggested that many care home providers still struggle to deliver quality care in the advanced stages of the disease (CQC, 2010). In the last few years the provision of palliative care in care homes has been the focus of national and local initiatives (Froggatt, 2005) to enable people to be cared for in their

'homes' without the need for unscheduled hospital admissions at the end of their life. However there has been limited evidence about the quality of dying for people with dementia within long term care settings (Peace, *et al.* 2007).

The National Institute for Health and Clinical Excellence (NICE) (2006) guidelines acknowledge that dementia care should incorporate a palliative care approach from the time of diagnosis until death (NICE, 2006) regardless of where the person dies. This should include a consideration of physical, psychological, social and spiritual needs of the person with dementia and the person's family. The National Council for Palliative Care (NCPC) has recognised the need to improve the end of life care for people with dementia but also acknowledges the challenges and additional resources required to meet the needs of this group of people (NCPC, 2010a, 2009a, 2009b).

One of the emerging major problems for clinicians is defining the 'dying phase'. In recognition of this, prognostic indicator guidance has been developed in the UK in an attempt to assist generalist practitioners to identify earlier when people with life limiting diseases enter the end stage (GSF, 2011; Thomas, 2010a, 2010b; DH, 2008). The 'end stage' of dementia is often presented as a gradual spiral of decline in people in the advanced stages of the disease which may or may not be accompanied by a medical event (Harris, 2007; Hughes, 2006; Katz and Peace, 2003; Sidell and Komaromy, 2003; Woods, 1989). If the prognosis is not clear, discussions of dying may not be initiated between the health professional, the person with dementia (if possible) and with the person's family (Parker and Froggatt, 2011). As the disease reaches the advanced stages and communication abilities decline (Sabbagh, *et al.* 2011; Regnard and Huntley, 2006) it can often lead to difficult decision making for

health professionals, relatives and carers as they debate the merits of whether to initiate, continue or withdraw active care and/or palliative care (Hertogh, 2006).

1.5 The Department of Health End of Life Care Strategy

The Department of Health (DH) End of Life Care (EoLC) Strategy attempted to apply the hospice model of care to generalist care within primary and community care services including care homes (DH, 2008). It emphasised the need to provide high quality care for all those approaching the end of their lives whatever their condition and whatever setting in which they may reside (DH, 2008). The approaches were based on sharing good practice, evaluation, measurement of improvement and training and education (DH, 2008), to replace the previously ad-hoc palliative and terminal care delivered by individual General Practitioners (GPs) and district nurses (Duffy and Woodland, 2006). The overall aim was to educate generalist health professionals, supported by specialist palliative care personnel, in all care environments, including the patient's own home. The programme promoted three possible models of care to deliver palliative care in a variety of 'non hospice' care settings (DH, 2008): The Gold Standards Framework (DH, 2008), the Liverpool Care of the Dying Pathway (Ellershaw and Wilkinson, 2011, 2003), and the Preferred Priorities of Care (DH, 2008).

1.5.1 The Gold Standards Framework

The 'Gold Standards Framework' (GSF) was developed by Dr Keri Thomas with support from the NHS Cancer Services Collaborative and Macmillan Cancer Relief and presents guidelines, mechanisms and assessment tools for community palliative care practitioners (Thomas, 2010a, 2010b; DH, 2008; King, *et al.* 2005;). Originally

developed for cancer patients, the GSF is now recommended for all chronic health conditions, including dementia. The GSF framework promotes the palliative care skills of generalists to support people and their carers/family members during the last year of life (DH, 2008, Thomas 2010a, 2010b). The intention is to commence a palliative care approach much earlier in the disease process using the prognostic indictor guidance which provides prompts to generalist clinicians, including GPs, to make them more aware of when to initiate supportive measures for end of life care for malignant and non malignant disease such as dementia (Thomas, 2010a, 2010b). Current evidence suggests that the use of the GSF promotes communication and coordination between professionals (King, *et al.* 2005; NICE, 2004) but that further evaluation is required to test the effectiveness of the GSF, particularly for those with non cancer conditions (Thomas, 2007).

In 2004 the GSF was adopted and piloted for use in care homes to develop staff and improve the care provided to residents at the end of life (DH, 2008). However the workforce in a care home has unique differences from mainstream health care providers; there are usually fewer registered nurses and the majority of personal care is carried out by support workers (Partington, 2005). Support workers have varying degrees of formal training which could impact upon palliative care provision.

1.5.2 Liverpool Care of the Dying Pathway

The Marie Curie Centre, Liverpool and the Royal Liverpool and Broadgreen University Trust developed the Liverpool Care Pathway for the Dying Patient (LCP) in the 1990s to promote the best of hospice care into other general health care settings which includes care homes (Ellershaw and Wilkinson, 2011; 2003) to support people

during the last few days/hours of life. It has been adopted into mainstream practice across the world and has been recommended by NICE (NICE, 2004). The LCP is based on an integrated care pathway to transfer a hospice model of care into other care settings (Partington, 2005). It involves structured care plans which detail essential steps in the care of patients with specific conditions (Higgins, 2010). The LCP generic document is designed for comfort care to be delivered in the last few hours and days for someone with life limiting illness by non specialist professionals (Ellershaw and Wilkinson, 2011; Ellershaw and Murphy, 2011).

In care homes the resident may take much longer to die and some adjustment is therefore required to facilitate its use in these settings (Partington, 2005). The LCP has been found to provide an opportunity for care home staff to consider the death and dying of the resident and identify additional resources that may be needed to offer good end of life care (McClelland, *et al.* 2008; Hockley, *et al.* 2005). Ellershaw and Murphy (2011:15) state that the LCP generic document 'is only as good as the teams using it' and requires a 'robust continuous learning and teaching programme to underpin its implementation and dissemination.'

Hughes, *et al.* (2007) state that there is also a lack of good quality evidence to support any particular approach for palliative care in dementia due to the complex and unpredictable nature of the disease trajectory.

1.5.3 Preferred Priorities of Care

Preferred Priorities of Care (PPC) is an ambulatory document that the patient holds, which can be taken into different care environments (DH, 2008) emphasising patient

choice, death as a social reality and ACP (Woods, 2007). Its aim is to ensure a seamless continuity of care and provide an opportunity to discuss issues relating to death and dying for patients with poor prognosis due to life limiting disease. Froggatt (2005) suggests that for older people in a care home, preferred place is usually between remaining in the care home and being admitted to hospital. Inappropriate hospital admission at the end of life has been recognised as a particular problem, not only as a resource issue but also acknowledging the 'acute' environment as not being able to meet all the needs of the dying patient (Baldwin, 2011). Fragmented and uncoordinated end of life care for people with dementia has been cited as a risk factor for inappropriate hospital admissions (Sampson, *et al*. 2012; Sampson, *et al*. 2011; Lawrence, *et al*. 2011; Lindstrom, *et al*. 2011b).

1.5.3.1 Advance Care Planning

The World Health Organisation (WHO, 2011:41) described ACP as a 'discussion about preferences of future care between an individual and a care provider in anticipation of future deterioration'. The Department of Health (DH, 2007:4) clarified ACP as 'a process of discussion between an individual and their care providers irrespective of discipline ... which takes place in the context of an anticipated deterioration in the individual's condition in the future with an attendant loss of capacity to make decisions and/or ability to communicate wishes to others'.

The benefits of ACP are viewed as providing an opportunity to anticipate future decisions relating to health and care needs, allowing the person to feel in control, make choices and provide an opportunity to initiate timely palliative care in life limiting conditions (Hertogh, 2006; DH, 2010). However discussions such as these

can be distressing to some people, especially if the health and or social care professionals do not have the appropriate training or interpersonal skills (DH, 2010).

The point at which an ACP becomes imperative to the person with dementia often involves recognition of the terminal phase of the disease, which, as referred to earlier in this work, can be problematic for health professionals. Dying with dementia is associated with aggressive medical interventions rather than a palliative approach (Downs, 2011). Difficult decisions often relate to the continuation or withdrawal of medical treatment and interventions such as medication, feeding tubes, treatment for newly diagnosed conditions and the appropriateness of other investigations, such as blood tests, which may not be appropriate to the dying person (Hov, *et al.* 2011; Hughes, *et al.* 2007).

ACP has a role to play in ensuring quality terminal care, but does not guarantee it (Downs, 2011). Ideally ACP should be undertaken with people with dementia before they become incapacitated (Lindstrom, *et al.* 2011a, 2011b). Under the terms of the Mental Capacity Act (MCA, 2005) formalised outcomes of the ACP might include one of the following (Barber, *et al.* 2012; DH, 2010), advance statements to inform subsequent best interests decisions, advance decisions to refuse treatments which are legally binding if valid and applicable to the circumstances in hand, appointment of 'Lasting Power of Attorney' (health and welfare and/or property and affairs). Less formally the person may wish to name someone whom they wish to be consulted if they lose mental capacity. This is only relevant to the care and treatment to a person once they have lost mental capacity to make decisions about any future care and treatment options.

There is limited evidence that ACP could potentially contribute to timely palliative care interventions (van der Steen, 2010). However it is accepted that knowledge about a person's preferences for end of life care can be beneficial when planning future care (Hughes, *et al.* 2007; Hertogh, 2006). Due to the sensitive nature of ACP discussions this can cause distress if not facilitated by appropriately trained staff (DH, 2010). Hughes and Baldwin (2006:104) advocate 'good quality and truthful discussions to avoid complaints when difficult decisions have to be made'.

1.5.4 The North West National Health Service End of Life Initiative

In 2007-2008 the North West NHS (NW NHS) commissioned a study which involved an evaluation of the implementation of the Gold Standards Framework (GSF) (DH, 2008) and Liverpool Care of the Dying Pathway (LCP) (Ellershaw and Wilkinson, 2011, 2003) for people with dementia in five pilot care settings across Greater Manchester. Four care homes from the independent sector and one from NHS Pennine Care Trust were chosen to implement a hospice philosophy, utilising the GSF and LCP as the basis of end of life care, for people with advanced dementia. An education and training programme was undertaken by the NW NHS Greater Manchester project team in the five care settings to introduce and facilitate the implementation of the end of life care initiative. Following implementation of the GSF and LCP in the five long term care 'pilot' sites in 2005-2006 an evaluation was commissioned and undertaken by a team from Liverpool John Moores University (LJMU). The evaluation took place during 2006-2008, and included one researcher, two co-investigators and one project manager who were initially assigned to undertake the study. As the appointed researcher, I was responsible for the design and

development of research methods and data collection, which included questionnaires to various groups, interviews and focus groups. This responsibility also included the management and analysis of collected data and the completion of the interim and final reports (Ashton, *et al.* 2009; McClelland, *et al.* 2008).

A non-experimental case study approach incorporating mixed methods was adopted. A range of people were involved in the implementation of the end of life care tools within the five care settings. This included staff directly involved in the care settings; Registered Nurses which included Registered Nurses (General) (RN) and Registered Mental Nurses (RMN), Health Care Assistants (HCA), Managers, Consultant Psychiatrists, Representatives of the Primary Care Team/Palliative Care Team and the Lead Enhanced Care Facilitators/End of Life Care Project. Two hundred care staff within the five care settings were identified through duty rotas, by the care setting managers. Care home managers provided details of the 22 General Practitioner (GP) practices, two Consultant Psychiatrists and one out of hours GP service provider, who were identified as providing medical support to the five care settings. The NW NHS end of life care facilitators provided the details of the twenty seven members of the Multi-Disciplinary Team (MDT) (other than GPs) who were involved in an external capacity to the five care settings. Specialist practitioners who supported the adoption of the end of life care tools within the five settings included Advanced Nurse Practitioners, LCP/GSF Facilitators, Pharmacists, Community Nurses, Macmillan Nurses and Chaplains. A wealth of data were collected as part of the evaluation of the initial NW NHS project (Ashton, *et al.* 2009; McClelland, *et al.* 2008), and the main findings are summarised below.

There was general agreement from all participants (care setting staff, medical staff, MDT members) to indicate that ACP is an individual process and discussed only as and when it meets the needs of the resident/patient. All care setting participants agreed that ACP promotes good communication and an understanding of the wishes of the resident as seen through the eyes of their family caregivers. However study participants agreed that ACP is an individual issue and should only be commenced when the family caregivers are ready to discuss it. The ideal situation that some participants suggested would be for the resident to be admitted with an ACP already in place which could have been completed in advance of their deteriorating mental state. This would ensure that it is the resident's wishes that are being facilitated and not the family caregiver's interpretation of it (Ashton, *et al.* 2009; McClelland, *et al.* 2008).

Participants acknowledged the emotional context in which family caregivers were involved during the admittance of their relative to a long term care setting but also the decision making process at the end of life for the person with advanced dementia. Changes of mind, requesting hospitalisation and misunderstandings were issues, although infrequent, did occasionally need to be discussed at length with family caregivers. Some study participants agreed that family caregivers have been challenging, particularly in the early stages of implementation and meeting their needs had been a 'trial and error' issue at times. Participants were generally optimistic that most issues could be resolved but that there would occasionally be some disagreement. Participants suggested that ACP is beneficial to identify the disease trajectory, to prepare for the death of a relative and identify personal choices and preferences that the resident/patient may have. Participants also expressed a need

to fully appreciate the impact of the Mental Capacity Act (MCA, 2005) and how this might influence end of life care planning (Ashton, *et al.* 2009; McClelland, *et al.* 2008).

ACP can have an impact on the reduction in hospitalisation and in the use of specific medical interventions (Gandy, *et al.* 2010; Herbert, *et al.* 2006; Froggart and Payne, 2006; Watson, *et al.* 2006). It should also be acknowledged that ACP is a high level communication skill. Open and honest discussions on sensitive issues did, according to the care setting staff, improve the experience of end of life care for the person, the family caregivers and the staff. Although often an uncomfortable process, participants did accept that it assisted carers/family members to prepare for the death of their relatives and prompted a discussion on the treatment and care options. However, participants did express some reservations on the timing of such discussions particularly with long standing residents and that the care staff would benefit from further education and training to facilitate the full adoption of the process (Gandy, *et al.* 2010, Ashton, *et al.* 2009; McClelland, *et al.* 2008).

The limitations of this evaluation study should be acknowledged. The evaluation of the NW NHS initiative was undertaken in five care settings only. This was a small scale initiative and therefore may not reflect what occurs in other locations or care settings. The planned intervention within the five care settings may not be replicable if the criteria for inclusion was threatened, or the care settings did not have the necessary resources to implement all aspects of the end of life care tools and initiatives. This evaluation, shortly after implementation, may have resulted in initial favourable outcomes but to what extent these are sustainable in practice is not known.

To monitor sustainability a further longitudinal evaluation study would be useful following the withdrawal of the NW NHS project team to address issues of resources and compliance with the interventions and a long term follow-up.

Further limitations are that the evaluation was restricted to the perspectives and experiences of health professionals about ACP and those of family caregivers or the older people with dementia were not explored. Care setting staff acknowledged that ACP ideally should be undertaken with people with dementia preferably prior to admittance to the nursing home. As this was not a common occurrence, and as the person often no longer had capacity, following admission to the nursing home, to participate in the discussions, this was then often left to the family caregivers.

These findings and gaps in knowledge were the basis that led to and has informed this PhD study, which has addressed the question of investigating ACP from the perspectives of family caregivers.

1.6 Summary of Chapter One

Despite the promotion of good practice within palliative care, many conceptual and ethical issues remain (Woods, 2007) and there exists some controversial and complex issues related to appropriate care and treatment at the end of life. The introduction of the end of life care pathways have attempted to implement essential steps based on evidence and multi-disciplinary experience to improve end of life care in all care settings. Care pathways are structured care plans which detail essential steps in the care of patients with specific conditions (Higgins, 2010) and have been introduced to improve equity of access to treatment and care, which includes end of life care.

There is also persuasive evidence that the care of people with dementia at the end of life is less than satisfactory (Hughes, *et al.* 2007). The current challenges to the full implementation of the Department of Health end of life care strategy (DH, 2008) includes, the difficulties in identifying the needs of people with unpredictable disease trajectories including dementia, the challenges and reluctance of clinicians to communicate with patients about prognosis and end of life care decisions, and the limited interaction between generalist and specialists health care teams (Addicott, 2010). Many people with dementia are still not deemed to have specialist palliative care needs and their care is often left to the generalist. There is also the added difficulty of communication difficulties and diagnosing the dying phase. The GSF does attempt to identify prognostic indicators that can guide physicians to 'diagnose' the terminal phase, and through the use of a care pathway map to identify appropriate interventions to relieve suffering as a result of bodily decay. It is too early to report if this is used consistently throughout the UK in all settings and if the interpretation of individual nurses and medical staff of 'suffering' is consistent.

1.7 Thesis Outline

The main aims of this study was to describe the use of the end of life care pathways, and in particular the use of ACP from the perspective of the immediate family caregivers of people with advanced dementia who are at the end of life and the professional care staff who facilitate these discussions.

Chapter two presents a review of the literature by outlining some of the main research findings related to end of life care for people with dementia. The results of the

literature review undertaken for this study centre around four central themes, dementia as a terminal illness, concepts of a good/bad death which includes treatment decisions at the end of life, ACP, and the experience of family caregivers when asked to make or participate in end of life decisions on behalf of their relative with advanced dementia.

Chapter three provides details of the research methods and procedures used within the study. This includes the use of interviews as an appropriate method of data collection to reflect experiences, and show how the appropriate selection of data analysis tools enabled experiences of the family caregivers to be reported. Ethical considerations are also discussed in detail to reflect the handling of sensitive topics relating to end of life care.

Chapter four gives details of the findings of the study of family caregivers and presents the results from the data collection, management and analysis. Direct quotes from respondents are displayed to support the emerging themes arising from the data. Similarities and differences within the findings are presented and the data interpreted.

In chapter five a discussion is presented according to the aims of the study, results and previous research as detailed within the literature review. This chapter also includes the limitations of the study, implications for practice and recommendations for further study. It also explores my own personal journey and reflection of undertaking semi-structured interviews on sensitive topics with potentially vulnerable people.

Chapter six presents the conclusions in consideration of the relevant literature and the findings of this study. Recommendations for improvements in policy, practice and opportunities for future research are presented.

Chapter 2: Literature Review on Dementia and End of Life Care

2.1 Introduction

This chapter will present a critical review of the literature in relation to the available research related to end of life care for people with dementia. The results of the literature review undertaken for this study have centred around four central themes; dementia as a terminal illness; concepts of a good/bad death which includes treatment decisions at the end of life; ACP and the experience of family caregivers when asked to make or participate in end of life decisions, on behalf of their relative with advanced dementia.

The following databases were searched: Ovid Medline, CINAHL, PSYCHlit and PSYCHinfo. Initially all relevant sources of empirical evidence, within the last fifteen years were identified which also included literature reviews, official reports (grey literature) and evidence based guidelines. Some attention was also given to government reports and well established non-governmental publications such as reports from the Alzheimer's Disease Society. The keywords, the databases consulted and the inclusion and exclusion criteria are summarised in Table 2.1. A summary table of all research studies reviewed in this literature review is located in Appendix 1.

Section 2.2 will include an overview of the literature which examines the issues of dementia as viewed as a terminal illness and how this impacts on the care given at the end of life.

Section 2.3 reviews the literature on the concepts of a 'good death' when caring for people with, and without, advanced dementia at the end of life and includes the management of symptoms at the end of life.

Section 2.4 is an overview of the current themes associated with ACP in palliative care for older people with and without dementia, and highlights some of the issues that can hinder advance planning discussions between older people and health professionals.

Section 2.5 examines the available literature relating to the ACP process and proxy decision making by family caregivers for people with advanced dementia at the end of life.

Table 2.1 Databases consulted

Keywords Boolean operators 'and' and 'or'	Databases	Number of studies selected
Section 2.2 Dementia, end of life, palliative care, terminal, hospitalisation	Medline CINAHL	12
Section 2.3 Good death, bad death, older people and people with and without dementia, spiritual care	PSYCHlit PSYCHinfo	16
Section 2.4 Advance care planning, older people, dementia,		21
Section 2.5 Advance care planning, proxy decision making, dementia, end of life.		8
Inclusion Criteria		Primary and empirical research, English language, nursing homes, hospice, hospital, residential care settings, research involving older people and people with dementia aged 65 years and over.
Exclusion Criteria		Opinion and editorial papers, pre 1997, delirium, research involving people under age of 65years (with and without dementia), domiciliary care settings, non English language.

2.2 Dementia as a Terminal Illness.

Death and dying is the single most important social factor of human experience, but in modern societies the responsibility of this has transferred from the friends and family of the dying person to the medical profession, namely nurses and doctors (Woods, 2007; Sandman 2005; Costello, 2004). This notion of death and dying as a

medicalised event is not new, Illich (1976) previously suggested that the concept of a natural death at the end of a healthy life is a medicalised ideal and that people are now required to die from a specific condition and die somewhere, usually in a medical environment, preferably within an allotted time frame.

Dying is characterised by the last period of life just before we die and has been associated with a causal chain of events leading up to and causing death (Sandman, 2005). This is often associated with the end of a long life or following a chronic or incurable illness. To be considered 'dying' and therefore in need of palliative care, people must fit into a set of criterion which is often set by health professionals, in particular doctors. The notion of dying resulting in a good death plays an important role within palliative care (Ellershaw and Wilkinson, 2011). Dying is a complex phenomenon and involves physical, emotional, psychological and social complexities and therefore a good death is difficult to define and predict (Conway, 2011; Costello, 2004). Conway (2011:71) suggests that 'instead of the culturally prescribed scripts of what the good death should consist of, the modern individual is left with uncertainty, doubt and fragmentation' and that death-related choices remain limited. Changes in the demographics of the population suggest that people now live with illnesses that are potentially fatal over a much longer period of time and that death happens when no one expects it and contributes to difficulties with prognostication and timing of palliative care interventions (Seymour and Horne, 2011).

A lack of agreement or acknowledgement that people were dying or deteriorating was studied by Di Giulio, *et al.* (2008) who reviewed the last month of life in severely demented elders in seven long term care institutions in northern Italy. Data were

collected from the clinical records of 141 patients with advanced dementia which included the last 30 days of life and the last 48 hours of life. The authors concluded that although adequate attention was given to the identification of physical suffering, almost half the patients had pressure sores in the month before death and pain was never measured on a specific scale. Ineffective management of pain was cited as contributable to the use of physical and chemical restraint. Di Giulio, *et al.* (2008) found that resuscitation (CPR), life sustaining intravenous drugs, tube feeding and some diagnostics were all used in varying degrees and suggested that a more aggressive than palliative philosophy was utilised within the settings. However it should be acknowledged that there was a reliance on documentation within the study and issues such as the level of accuracy and consistency between professionals should be considered. The study implied that there was no agreement of dying in the patient with advanced dementia. Although inconclusive the research does add to the acknowledgement that people with dementia may require a more proactive palliative care approach earlier in the disease trajectory. Goodman, *et al.* (2009) described this as a failure of professionals to recognise when a person stops living with dementia and starts to die from it and so influences decisions, when and if, to involve specialist palliative care services.

The previous study and the following studies (Mitchell, *et al.* 2007a; 2007b) also adds to the debate that dementia is worthy of a palliative care approach. However research from the USA cannot necessarily be viewed in isolation to its and other countries complex funding arrangements, which may influence decisions regarding early referral and availability of additional resources. In a larger study by Mitchell, *et al.* (2007a) the prevalence and factors associated with decisions to forgo hospitalisation

were examined in nursing home residents with advanced dementia in all Medicare and Medicaid certified settings in 48 States in America (USA) in 2000. The study concluded that the decisions to forgo hospitalisation orders (DNH) of USA nursing home residents with advanced dementia were uncommon (7%). This suggested a lack of a coordinated philosophy of palliative care approach to this group which often resulted in a more aggressive terminal care arrangement within a hospital setting. Within this study, specialist dementia units with appropriate nursing and medical staff, together with advanced directives influenced the decision to forgo hospitalisation, indicating that care setting staff within specialist dementia units had a better understanding of the disease and the individual needs of the person.

A lack of hospice referral in the US was found to be associated with the difficulties of prognostication. Mitchell, *et al's.* (2007b) study examined a repository of over 120,000 surveys collected nationwide in the USA in 2005 from bereaved family members whose loved ones died from dementia and received hospice care at the end of life. The goal was to contrast the experience of dementia to that of older people with other common terminal diseases and illness. Results indicated that only 11% of hospice patients had dementia and it was concluded that dementia is a far less common terminal condition among older hospice patients. The study found that prognostication was challenging in the patient with advanced dementia and this can make hospice referral difficult due to the requirement of an estimated life expectancy of less than six months in the USA. Improvements were identified (as reported by the relatives) which included the need for more emotional support for relatives, better coordination of care and more information on what to expect during the dying process.

Sampson, *et al.* (2012) examined the barriers for people with dementia and their carers in accessing good quality end of life care in the London Borough of Harringey following a rapid participatory appraisal. Qualitative interviews with seven carers and focus groups with 50 care staff reported that acute hospital admission was common in the last six months of life and no record was found of the palliative care team being involved. The study also suggested that little support was available to families and care home staff after bereavement. This study and the previous studies are useful to inform professionals of the need for earlier interventions of the palliative care team across different levels of practice.

The literature suggested that there was a lack of agreement and often even acknowledgement amongst health professionals when people with dementia are terminally ill and may benefit from a planned palliative care approach. Family caregivers need to know what to expect when their family member has dementia to enable them to prepare for all eventualities. The need to improve knowledge about the disease trajectory of dementia and recognition of the dying phase are important factors when planning end of life care.

2.2.1 Characteristics of Clinical Indicators for Palliative Care

The lack of agreement concerning the identification of the patient's death trajectory is particularly relevant for people with chronic illness such as those with dementia, where is it is difficult to identify at what point the person could be considered to be 'dying'. Glaser and Strauss' (1965) study of the social organisation of dying and death in hospitals identified the 'career pathway' of the dying person and suggested that dying people enter social phases or critical junctures in the journey towards death

from the diagnosis to death. Glaser and Strauss (1965) suggested that care is controlled and mapped out by doctors and nurses to fit their expectations of a particular disease or illness. Patients are then expected to die within their allotted trajectory to enable a good death (Morrell, 2009), during which a variety of technical fixes are used for medical problems dying people often present with (Downs, 2011). This suggests that there are clinical indicators which can alert the health professional to acknowledge the person is moving towards the end of life and dying phase. This would be particularly relevant when planning or justifying referral for hospice care or palliative care in generalist settings which may have resource implications.

The Gold Standards Framework (DH, 2008) includes prognostic indictor guidance for generalist clinicians, with a specific section on dementia. This attempts to provide prompts, to increase awareness of when to initiate supportive measures for end of life care (GSF, 2011). The GSF (DH, 2008) has been described as having 'considerable potential to improve end of life care but that further work is needed to support its uptake and consistency of implementation (Shaw, 2010:317). Van der Steen (2010) in a review of the literature on dying with dementia suggested that prognostic indicator tools may help to estimate prognosis but that they do not often provide estimates for those of high risk of death and that there is a need for further clinical impact studies in palliative and dementia care settings.

The following studies, although inconclusive, attempt to identify clinical indicators which may support professionals in how to identify when a person with advanced dementia may require a more active palliative care approach. Mitchell, *et al.* (2004a) created a practical risk score to predict six month mortality within recently admitted

nursing home residents with advanced dementia. The study was conducted in all Medicare or Medicaid licensed nursing homes in New York and Michigan (n=634) during 1994-2000. A total of 6799 residents were included in the analysis. The study confirmed that the characteristics which are indicative of poorer survival in advanced dementia include older age, greater functional impairment, maleness, poor nutritional status, diabetes and cardiovascular disease. The study concluded that there is a need to plan for the end stage of dementia so that palliative care can be effectively resourced and delivered.

This lack of awareness or consensus of opinion within the care team, of when the person enters the dying phase, can result in the hospitalisation or transfer to an acute setting. Place of death of older people with dementia in Europe was studied by Houttekier, *et al.* (2010). The study involved the examination of the death certificate data in 2003 within five European countries (Belgium, Netherlands, England, Wales and Scotland). This collective database was facilitated by the 'Dying Well in Europe' european collaborative research project. Country variation in hospital death was reported as considerable. In all the countries studied a 'substantially' greater proportion of patients with dementia died in hospital (n=22.7 (46.3%)) rather than in a nursing home. The exception was the Netherlands, were a much smaller percentage (2.8%) (Houttekier, *et al*, 2010:753) were transferred and died in hospital. Patients with dementia were less likely to be referred to palliative care services, or often referred late in the stage of the disease, which suggests a lack of ACP and difficulties with prognostication due to the less distinctive terminal stage. It was suggested that the Netherlands has developed well-equipped nursing homes to deal with the long duration and burdensome care of people with dementia to prevent unscheduled

hospital admissions as a place of death. These hospital admissions may also suggest a lack of confidence in care setting staff to make decisions which will enable them to adequately care for the resident with dementia and manage distressing and complex symptoms at the end of life. If health professionals are to avoid unscheduled hospital admissions then the availability of resources, access to medical services, education and training of health professionals are important factors in the end of life care for people with dementia. Further work is required to understand the full potential of specific care environments to avoid the unscheduled transfer of people with advanced dementia to hospital settings.

The knowledge and skills of care staff caring for patients with advanced dementia was studied by Mitchell, *et al.* (2009) in Boston (USA) nursing homes. Subjects were recruited during 2003-2007 from 22 nursing homes with more than 60 beds each. This study was known as the CASCADE study (Choices, Attitudes and Strategies for Care of Advanced Dementia at the End of Life). This was a prospective cohort study of nursing home residents with advanced dementia and their families. A variety of data collection methods were used which included nursing documentation, interviews with nursing staff, and physical examinations of the residents at regular intervals. A range of clinical complications were identified from chart reviews, which also included the date on which the resident experienced this condition. The clinical complications included pneumonia, febrile episodes, eating problems and acute medical conditions, for example, hip fractures. During the analysis stage the study examined the overall mortality, survival and risk of death with the cumulative incidence of these clinical complications. The resident's family (identified as the health care proxy) perception of prognosis was also obtained and recorded from an

interview prior to the resident's death. Results indicated that more than half of the residents (323 residents) died over the 18 month period and most of the deaths occurred in the nursing homes. The results concluded that residents with advanced dementia have a high mortality rate, that infections and eating disorders were likely to develop in the terminal stage and that distressing symptoms were common and increased as death approached. Many residents also underwent burdensome and aggressive interventions which Mitchell, et al. (2009) describe as of 'questionable benefit'. These included intravenous therapy, hospitalisation and tube feeding. This also confirmed that there was a lack of understanding of the terminal stage of dementia and a need to develop an understanding of the prognosis, expected complications and how these precipitate the dying phase. Mitchell and colleagues (Mitchell, et al. 2009) accepted that the nurses' records may be inaccurate and pain may be under-recorded. The sample was also limited to the Boston area. The study has potential to raise awareness within professional groups and the themes would appear similar to those found in other international studies (Houttekier, et al. 2010; Lloyd-Williams and Payne, 2002). It is difficult to generalise findings as the results are dependent on the previous education and training and skills of nurses in a variety of settings, both national and international, and how these might impact upon the quality of care given and received.

The important consideration here is that Mitchell and colleagues (Mitchell, et al. 2009) highlight that clinical indicators exist that have the potential to inform relatives, nursing and medical staff that the resident's condition was moving towards the terminal phase and that prognosis was poor. Poor communication and professional hierarchies have also been cited in UK research to suggest that this could be

responsible for the lack of discussions and the earlier transition towards a palliative approach during the chronic or terminal disease trajectories (Gott, *et al.* 2011)

In an attempt to highlight and reduce inconsistencies when planning care for dying patients, Lloyd-Williams and Payne (2002) conducted a retrospective study of 27 deaths occurring in a long stay unit of a large psychiatric hospital following the implementation of multi-disciplinary guidelines to improve care in the terminal phase of dementia. The study was conducted in response to an audit which surveyed the palliative care given to patients dying of end-stage dementia on long stay wards. The results of the audit suggested that patients had many symptoms for which no palliation was given, which included infrequent use of analgesia. The audit also highlighted the widespread use of antibiotics in the last few days or weeks of life. These guidelines were developed with the cooperation of the unit's multi-disciplinary team and included a stepwise management of the most common symptoms occurring in the last weeks of life, for example, pain, dyspnoea and pyrexia. Twelve months following implementation of the guidelines, the results suggested that pain was more likely to be managed effectively, antibiotics were less likely to be prescribed and that advice was sought from appropriate palliative care teams. Despite being a small scale study, the authors suggested that there is a need to develop partnerships in care and examine which skills and knowledge are useful to provide a collaborative approach to palliative care for patients dying from dementia. Further work is required to understand the full potential of a multi-disciplinary approach to palliative care for this group of patients.

An attitude questionnaire survey method was used by Coetzee, *et al.* (2003) to study the attitudinal differences in care priorities between carers and psychiatrists towards end of life treatment decisions in people with dementia. The study took place in Nottingham (UK) and 148 carers and 34 clinicians responded to the questionnaire. The study's findings suggested that clinicians favoured active treatment of potential fatal illness at the end of life less than carers who valued patient centred issues such as the importance of dying with dignity.

Input from family caregivers in end of life care arrangements for people with advanced dementia in Japanese care settings, was studied by Nakanishi and Honda (2009). Thirty three cases were included in the study from care homes. They found that when family carers are involved in the decision making process this can affect decisions relating to reduce hospitalisation and the need for invasive tube feeding. The importance of dignity in death, as perceived by family caregivers has been demonstrated in other studies (Lamberg, *et al.* 2005). Clearly more research is required to identify factors which may influence health professional's attitudes on when to initiate a palliative care approach.

2.2.2 Summary of Dementia as a Terminal Illness

Within the literature there was recognition that dementia is a terminal condition but that it is still difficult to estimate life expectancy and the terminal phase. The previous studies, despite their limitations, highlighted similarities in the need for a palliative care approach for people with advanced dementia and have been useful in developing a shared belief amongst international researchers. The reliance on retrospective collection of data and the accuracy of documentation can be problematic when

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making assumptions about transferability of findings (Houttekier, *et al.* 2010; Nakanishi and Honda, 2009; Di Giulio, *et al.* 2008; Mitchel, *et al.* 2004a). It appeared accepted that individuals will display certain clinical indicators which may suggest that they are entering the dying phase; however, how these indicators are interpreted by health professionals also appears to be an individual explanation and may cause them to be cautious about diagnosing dying. Although not specific to dementia, in recent years, throughout the UK the GSF (DH, 2008) and the LCP (Ellershaw and Wilkinson, 2011) have attempted to identify prognostic indicators that can guide physicians to 'diagnose' the terminal phase, and through the use of a care pathway, map appropriate interventions to relieve suffering as a result of bodily decay. It is too early to report if this is used consistently throughout the UK in all settings and if the interpretation of individual nurses and medical staff of 'suffering' is consistent. This lack of diagnosing the terminal phase has implications for effective palliative care (Seymour and Horne, 2011) and has been highlighted by Birch and Draper (2008) who suggest an urgent need for education and training for all health care professionals and support workers. The role and relationship with the family caregiver in palliative care decision making is complex and will be discussed later in this chapter.

2.3 Concepts of a Good Death

Most people still die in institutions which is mapped by doctors and nurses on what they believe to be the normal pattern of people with similar disease or illness and this is influential in the care that people are prescribed (Conway, 2011; Morrall, 2009). Earlier work by Friedson (1970) and Zola (1972) drew attention to how the medical profession claims jurisdiction over the label of illness, irrespective of its ability to

deal with it effectively. However new institutional arrangements and initiatives to engage populations in the conversations on death and dying is according to Conway (2011) changing the way we think about death and dying.

Woods (2007) argues that an important feature of a good death is the quality of the dying person's experience prior to death, which is influenced by the judgements of others. Woods (2007) also suggests that the experience of those who survive the death, who have cared about the deceased person, is also an important consideration when reflecting on the concepts of a 'good death'.

Good deaths, as discussed in chapter one, were often described in terms of comfort, peaceful, pain free, dignified, autonomous, and free from distress and suffering (Baldwin and Woodhouse, 2011; Higgins, 2010; Addington-Hall and O'Callaghan, 2009; Sutherland and Stevens, 2008; Hughes, *et al.* 2006). Bad deaths were associated with poor management, stress, uncontrolled pain and other bodily disintegration, poor communication, organisational and structural constraints (rules and inflexible routines) and indifference by nursing staff and doctors (Higgins, 2010; Woods, 2007; Grande, 2009).

Long term conditions such as heart failure, chronic obstructive pulmonary disease and stroke follow a different pattern of the dying trajectory than those dying of cancer (Quigley, 2011). Cancer deaths often follow a period of decline several months before death, whereas deaths from long term conditions often involve unpredictable trajectories which often includes increasing exacerbations of acute illness (Quigley, 2011; Higgins, 2010).

A study by Small, *et al.* (2009) examined carers' views of dying, death and bereavement for family members who had recently died of heart failure. Although a small study this has the potential to add to the literature on the experience of care for non cancer conditions. Twenty interviews were conducted with bereaved carers of older people with heart failure. Dissatisfaction with the manner of death was focused around hospital care, particularly what they believed to be futile treatments. The authors concluded that elements which contribute to a good death include death at home, the plans for what the patient considers to be a good death, the need for a consensus of opinion between professionals, family carers and the patient when the terminal phase has begun and to prevent inhibition of these discussions, to view the patient in a social context. They also concluded that the experience of the carers is important for any after death care. Sloane, *et al.* (2008) conducted after-death interviews with staff who had cared for 422 residents with dementia in US nursing homes. The results suggested that although there were some inconsistencies in palliative care provision for residents with dementia the general consensus was that appropriate care for dying persons with dementia is generally provided in the nursing homes. However they did express some concern over the use of physical restraints, sedatives and the need to prevent skin ulcers which is a contradiction and is not consistent with quality care.

A study from van der Steen, *et al.* (2009b) in the Netherlands suggested that dementia patients die with great suffering often after pneumonia or as a result of prolonged intake problems. The study combined two sample populations; those who died with pneumonia and those who died with intake problems but with no pneumonia.

Discomfort was measured using the Discomfort Scale – Dementia of Alzheimer's Type (DS-DAT) (Hurley, *et al.* 1992) which is part of an assessment of quality of life in residents with severe dementia. Tube feeding, especially in the days before death, was associated with suffering. 'Suffering' can be a subjective emotion and therefore can be difficult to quantify. However the use of antibiotics was not associated with increased suffering but was suggested to be possibly beneficial as a palliative care option. What these and other studies show is that there is limited conclusive evidence about what is the most beneficial approach to palliative care. Further evaluations within different care settings and across different cultures would be beneficial to examine what works most effectively to meet the palliative care needs of people with advanced dementia.

Sandman (2005:27) suggests that there is not, and never can be, a singularly adequate account of the 'good death' and those alternatives are the 'least bad death', the 'good enough death', the 'personally ideal death' and the 'quality of life until death' death. The experience of an individual's death, and for those who witness it, is as individual as each individual birth. Limited research on this issue that primarily relates to people with dementia involves evidence from family caregivers who have witnessed dying and who have reported how the death was managed.

2.3.1 The Good Death – Identifying the Need for Palliative Care

Palliative care is idealised as a contributing pre-requisite for the good death. The focus of care is to move away from attempting to cure or prevent dying but to improve the quality of life until death through the prevention and relief of suffering (Higgins, 2010). Palliative care according to the World Health Organisation (WHO,

2002:1) 'improves the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement'.

This model of care has been adapted to be used for people with longer periods of illness and unpredictable disease trajectories to support the person through the journey of a terminal illness (Sutherland and Stevens, 2008). However, little is known about the quality of death and dying in dementia due to the complexity of the disease trajectory. What is known is that quality of life is influenced negatively by behavioural and psychological factors (depression, agitation, disinhibition and irritability) during the course of the disease (Hurt, *et al.* 2010, Banerjee, *et al.* 2006) and there is little evidence to support how this is managed as the disease progresses towards the end of their lives (Banerjee, *et al.* 2009). The National Council for Palliative Care has also recognised the need to improve the end of life care for people with dementia but it also acknowledges the challenges and additional resources required to meet the needs of this group of people (NCPC, 2010a, 2009a, 2009b).

In a critical review of the literature from the previous ten years (1996-2007) by Birch and Draper (2008) it was suggested that the development of palliative care for people with dementia, especially those entering the terminal phase, will require sufficient resources and training to ensure quality and equity at the end of life. The following studies confirm these issues of quality and equity and although not conclusive can add to the general debate on what is required to facilitate the 'good death' for people with advanced dementia.

Seymour, *et al.*'s (2002) study used focus groups of older people to examine the concepts of a good death. The use of morphine and terminal sedation was the focal point of discussion for the focus groups. The authors acknowledge that this was an initial exploration of how older participants prioritise issues associated with innovative technologies in care. Eight focus group discussions were held with 32 participants recruited from six selected community groups representing older people in Sheffield. The general findings were that there was a consensus of opinion among participants that the relief of pain and other distressing symptoms was a basic element in the good care of dying people. One of the participants had witnessed her mother die from dementia and cited how her mother had 'struggled' for several days prior to death and how terminal sedation may have avoided her mother's and her own distress. A further comment from this participant also suggests pain control was not fully understood in her mother's case. The authors suggested that a 'good death' is one which suits the preferences of the dying person and their close family which is balanced with the protection of integrity and the values of the professional carers. The authors conclude that death is a managed process in which clinical practices are enacted, regulated, observed and interpreted and that what is good or bad, better or worse, may only be determined by the social relationships surrounding the dying person, which could be, interpreted as the 'least worse death' (Sandman 2005:27).

An innovative model of providing quality palliative care for dementia patients and their caregivers was described by Shega, *et al.* (2003). The Palliative Excellence in Alzheimer's Care Efforts (PEACE) programme responded to previous studies within the United States that revealed that persons with dementia are infrequently referred to a hospice. The setting within this study was a primary care facility in Chicago

providing care to 2200 older adults. There were 150 patients recruited for the PEACE programme. Initial results for this study indicated that satisfaction was reported by patients and families which suggest that appropriate advance planning and functional assessment tools facilitate good care. Good end of life care included adequate pain control, attention to prior wishes, patient dying in desired location, appropriate hospice referral, and stress reduction for the caregiver. This is also supported in a study by Casey, *et al.* (2011) who examined key stakeholder's and direct care manager's perspectives on the current provision of care for older people in acute and long stay care settings in Ireland. The intention was to construct a model for 'dying well', using a qualitative design involving 33 staff working in six settings. Philosophy, culture and organisation of care, knowing the person, the physical environment and resources were all sited as influential factors which have the potential to impact upon the quality of care that older people receive. The above studies are useful to inform practitioner education and how to improve practice. However further work is required to evaluate the implementation and impact of palliative care interventions.

A patient dying in their preferred or desired locations as a prerequisite for a good death may or may not include hospitalisation. Lamberg, *et al.* (2005) studied decisions to hospitalise in a sample of 240 residents in teaching nursing homes who died during 2001-2003 with advanced dementia in 675 nursing facilities in Boston (USA). Do Not Hospitalise (DNH) orders were examined to identify the potential factors associated with having such orders for people with advanced dementia. Results indicated that DNH orders at the time of death were common (83% of subjects) but that often these were more prevalent when death was imminent (30 days

before = 50%). Twenty five per cent of residents were transferred to hospital during the last six months of life. Potential factors which influence DNH orders included, age (92 years or older), previous length of stay in the facility of two years or longer, total functional dependence, eating problems and having a surrogate decision maker who was not the subject's child. Only four subjects who had DNH orders were hospitalised and this was as a result of hip fractures (n=2), acute arterial leg embolus (n=1) and major gastrointestinal bleeding (n-1). Family surrogates were more likely to choose palliation if the resident had been institutionalised for a long period prior to deterioration and eating problems were a signal of nearing death. In these situations families may be more likely to appreciate the need for comfort care. The emerging picture from this study highlights important features of the dying resident but also raises further questions relating to the reliability and relationship of the surrogate decision makers and the impact of early intervention of palliative care for individual residents which may or may not have influenced decisions.

Assessment of pain was also the subject of a study undertaken by Chen, *et al.* (2010). The purpose of this study undertaken in six dementia units in Northern Taiwan compared the pain reporting amongst registered nurses and nursing assistants. As could be predicted, due to their additional knowledge and training, the registered nurses assessment of pain was considered more reliable than the nursing assistant's. Although a limited study it was useful to highlight the need for appropriate pain assessment scales but it could not be sure what worked effectively. Other validated pain scales are available and include the Pain Assessment in Advanced Dementia (PAINAD) (Warden, *et al.* 2003) and the Abbey Pain Scale (Abbey, *et al.* 2004) however, the literature suggested that the reliability and consistency of use of any

pain scales needed to be further researched to identify the accuracy of any observation

or pain scales (Chen, *et al.* 2010; van der Steen, 2010).

A good death and the experience of suffering are open to interpretation. There is a

need for the continued education and training for care staff and a change in attitudes

towards the recognition for potential suffering for people with dementia. The need to

ensure consistency of use and competency of completion is essential when facilitating

the completion of any form of rating scales. Rating scales can be open to

interpretation as is the understanding of 'suffering' which is often instrumental as to

when and how palliative or active interventions are chosen and implemented.

2.3.2 End of Life Care Interventions and Treatment

Challenging ethical problems often arise over the appropriateness of utilising medical

technology and aggressive treatment regimes for the dying (Woods, 2007). When the

disease does not follow predicable patterns, as in dementia, and the accuracy of the

death cannot be predicted, the appropriateness of interventions becomes even more

complex. Lawton (2000:133) describes the 'disadvantaged dying' where cancer

patients are often afforded a special status rather than those suffering from chronic

degenerative disease. Poorly managed symptoms prior to death confirm the lack of

acknowledgement of the dying phase and the possible inappropriate use of aggressive

interventions.

McCarthy, *et al.* (1997) conducted a study in the UK to describe the last year of life

of people with dementia. The study's aim was to identify the symptoms, care needs

and use of a satisfaction with health services and the bereavement state of the

respondent. The Regional Study of Care of the Dying was collaboration between 20 regional health authority districts in England which sought to record the needs of dying people as a basis for health service planning. This retrospective study used death certificates to identify 170 patients with dementia and 1513 cancer patients. Informal carers and relatives were interviewed approximately ten months after the death of the patient. Symptoms, care needs and a satisfaction with health services and the bereavement state of the respondent were compared between the two groups. The authors found that patients dying with dementia have symptoms and health care needs comparable with cancer patients; mental confusion (83%), urinary incontinence (72%), pain (64%), low mood (61%), constipation (59%) and loss of appetite (57%). Dementia patients also saw their GPs less often than cancer patients. The authors concluded that greater attention should be given to the palliative care needs of dementia patients and education may facilitate the identification of when a palliative care approach should commenced.

The following studies contribute to the debate on end of life symptom management but they do not adequately identify the ethical, moral and legal arguments and dilemmas that contribute to decision making on withholding or withdrawing medical or nursing care and treatment.

Preparation for death is as important as the dying phase itself. Formiga, *et al.*'s (2007) comparison study of dying in hospital of terminal heart failure or severe dementia, examined the circumstances associated with death and the opinions of caregivers. Included in the study were 102 patients over 64 years of age, with end stage dementia (37%) or congestive cardiac failure (64%). Caregiver's opinions on the

circumstances of death were also obtained. The group of dementia patients were older and had fewer hospital admissions in the year before death than the group of heart failure patients. Withdrawal of drugs and initiation of terminal care was only provided late, often less than two days, into the dying process. This suggested that dying was not recognised early enough for both groups. This has profound indications for symptom control and the decisions regarding appropriate interventions and treatments. The emphasis on comfort care rather than burdensome and painful measures would suggest the need for a more transitional strategy for an easeful painless death.

In a retrospective explanatory study in Italian long term care settings, Di Giulio, *et al.* (2008) found that interventions which included, antibiotics, aniolytics, artificial hydration and nutrition (AHN), development of pressure sores, tube feeding and physical restraint all featured in the last 48 hours of care. The study included 141 patients in seven Italian long term care settings (referred to earlier in this chapter) which not only highlighted the lack of recognition of the dying phase of a person with dementia but also that symptoms that should be controlled and managed within a palliative care philosophy were not addressed for these patients. Regnard and Huntley (2006:37) suggested that nutrition and hydration 'rarely presents as an ethical dilemma', but rather a clinical issue to do with maintaining comfort. The suggestion is that stopping nutrition and hydration too soon does not necessarily result in a rapid deterioration. However concerns exist as to how this may or may not prolong discomfort.

As identified in chapter one McClelland et al. (2008) completed an evaluation of end of life care in four care homes from the independent sector and one NHS Care Trust in the UK which were chosen to implement a hospice philosophy utilising the GSF and LCP to aid and inform end of life care for people with advanced dementia. The GSF (DH, 2008) and LCP (Ellershaw and Wilkinson, 2011, 2003) provided a framework to develop interventions within these five long-term care settings. A series of education and training sessions were undertaken by the NHS North West Greater Manchester project team to the five care settings to introduce and facilitate the implementation of the end of life models of care. Nursing staff reported that some flexibility was required within the tools and pathways to meet the specific needs of people with dementia. Results also suggested that GPs in particular have an impact on retaining the dying person in the nursing home and that anticipatory prescribing was viewed as a key element in the management of pain and other distressing symptoms associated with the dying person. The evaluation team also reported that there was evidence that qualified staff were more prepared for the physical and cognitive decline and to support and manage the death of the resident/patient with advanced dementia. The suggestion being that appropriate interventions, education and training can impact upon the palliative care needs of this group. However it was acknowledged that interventions such as these cannot necessarily be replicated across settings due to the heterogeneous nature of different care settings (Badger, et al. 2011; Shaw, et al. 2010; Hewison, et al. 2009). It is also acknowledged that the limited numbers of sites where these end of life care initiatives were implemented means they may not be directly transferable or generalisable to all settings.

Studies suggest that there is an inconsistency with interventions, particularly with artificial hydration and nutrition, which can contribute to the potential for mismanagement of the person with advanced dementia at the end of life. There remains a lack of conclusive evidence about what is best practice across all settings. The current studies do not adequately address the ethical, legal and moral issues faced by health professionals in these circumstances in view of this lack of evidence. These studies do confirm a general lack of evidence to guide health professionals in their decision making and also to acknowledge that dementia is a terminal illness and an ultimate cause of death in some care settings. Without sufficient evidence, clinicians could base decisions on the quality of life of the person and if certain treatment regimes are followed this could be beneficial or detrimental to the comfort and care of the person with dementia who is at the end of life. The problem with this is that it implies inconsistency and is therefore open to interpretation of an individual's 'suffering'.

A concern expressed in the use of palliative care approaches often involves the use of medication for comfort care rather than active treatment. Parsons, *et al.* (2010) conducted a literature review regarding medication use in patients with advanced dementia who are nearing the end of life. Adverse reactions, contra indications and side effects from a cocktail of medication may cause more distress in the dying patient. The authors cite the contradictory evidence available to guide evidence based discontinuation of drugs such as acetylcholinesterase inhibitors, antipsychotic agents, antibacterial, antihypertensive, antihyperglycaemic drugs and anticoagulants. Accurate estimation of the patient's life expectancy is cited as a main factor in decisions to forgo treatment as physicians decide on when, and if, to change from an

active approach to a palliative approach. The concluding remarks of the authors suggest that significant work must be undertaken in the area of medication discontinuation in patients with end stage dementia who are nearing death.

2.3.3 Spiritual Care

Phillips, *et al* (2010:182) suggests 'spirituality involves a search for the meaning of life through the transcendence of the human experience'. The National Institute of Health and Clinical Excellence (NICE, 2004) recognised the importance of spiritual care as an essential part of palliative care. Spiritual belief is 'concerned with the existential or the ultimate meaning of life ... and may not be expressed in a religious way' (NICE, 2004:95). A person may be religious, but not spiritual, or spiritual but not religious (Phillips, *et al.* 2010). NICE (2004) acknowledges the need for all the health and social care team to appreciate the spiritual needs of people suffering life limiting disease. Although not directly referred to by NICE, there is a need to assess, plan and support patients who have dementia. Power (2006:27) identified that people in an advanced stage of dementia are not equal in terms of power to their care providers and that the challenge for all health and social care professionals is not to 'impose their own agenda, beliefs and preferences' in relation to spiritual and religious practice.

Issues of personhood and the value of life of the person with dementia, first described by Kitwood (1997) has been identified as important yet challenging, especially as they move towards the advanced stage of the disease (Killick, 2006; MacKinley, 2006). Communication and the ability to engage in everyday interests and activities

are often at the core of relationships which give life meaning. Spirituality is often associated with religious beliefs, rituals and practice (Power, 2006) and a person with advanced dementia may not be in a position to fully participate due to their cognitive impairment and communication loss. However it is becoming increasingly acknowledged that religious beliefs and practices may be only one dimension of spiritual care (MacKinley, 2006; Killick, 2006). MacKinley (2006:66) argues that people with dementia have spiritual needs and that in the later stages this may be the main level of communication and, 'to cut them off from the access to spiritual opportunities, for example, rituals, liturgy music, is to cut off a life line to their souls'. Suffering caused by dementia can last a long time and the person with advanced dementia can still express feelings that are relevant to self determination as communication fails (Dinning, 2006). Lawrence (2007) in a paper presented to a Special Interest Group in Spirituality and Psychiatry in 2005 (Faculty of Old Age and Psychiatry) identified that it is important to read through the 'silence' and respect the person's existence, their dignity as a human being and that they should have access to appropriate support. Lawrence (2007) also acknowledged that it is important to recognise the person as they are now, and not as they may have been before their illness, which Lawrence (2007) suggests is a 'life legacy' for the present.

Fargeau, *et al.* (2010) recruited 47 patients with Alzheimer's disease to participate in a study to examine changes in the self in relation to behaviour and memory and to explore in which dimensions the self impairment may appear. The 'self' was assessed using a semi structured scale along three dimensions; the material self, the social self and the spiritual self. Four items assessed the spiritual self which is of interest in this section of the chapter. 'Self' is described as the behavioural,

psychological, emotional and social features that distinguish each individual from any other (Fargeau, *et al.* 2010). Participants were recruited from the de Poitiers University Department of Neurology, France. Questions relating to the changes that were incurred in the spiritual self during the illness included participation in cultural activities, political interests, religious interests and expressions of moral opinions and behaviours. Although a relatively small study, the results indicated that the social self dimension (activities of daily living (ADL)) was more often impaired than the spiritual self dimension and that personal beliefs and values may still be retained until late into the disease. This adds to the debate that people with dementia, even towards the advanced stages of the disease, could have the potential to be approached to participate in discussions to identify their own wishes and values for the care they wish to receive at the end of life, despite having difficulties with communication and physical abilities for self care. It is difficult to generalise findings based on a small study and whether this is transferable across cultures and settings.

The following study also suggests that spiritual care is not always assessed in practice for people with advanced dementia. Brandt, *et al.* (2005) described the quality of palliative care provided in the last days of life in 16 Dutch nursing home' residents who were mainly non cancer patients, which included residents with dementia. The study was conducted in 2001-2003 and used a pre-validated Palliative Care Outcome Scale (Hearn and Higginson, 1999) to measure quality of care within the nursing homes. Questionnaires were completed by staff following the death of a resident. Four hundred and seventy one questionnaires were completed at death of which 60% of patients had dementia. The study relied on the report of proxies (nurses) and the authors accept they may have under reported or over reported aspects of palliative

care. The results indicated that physical care was mainly delivered appropriately and effectively. However results also indicated that nurses on average were more likely to assign a negative score or answer 'not known' to demented patients than to non demented patients for items which included issues of self worth, life worthwhile. The authors suggest this is an unmet need in the spiritual domain of the dying person with dementia. This lack of attention to spiritual care was also found in a study from Mast, *et al.* (2004) in which nine national (USA) developed guidelines for chronic, non curable and life-limiting disease were assessed to identify to what extent care was integrated. Ten per cent of guidelines had significant palliative care content, 64% had minimal content. The least addressed domains dealt with were, spirituality, ethics, and advocacy and family roles. However dementia guidelines did have an increased content in the domains of family roles and psychological issues and also ethics and law policy. The authors suggested that palliative care content needs to be strengthened within national guidelines which should include attention to spiritual issues. However a lack of documented evidence does not necessarily mean that spiritual care is not interpreted or delivered. Definitions of spirituality may differ across individuals, settings and cultures and need to be examined and explored.

A study by Jeong, *et al.* (2012) examined ACP in New South Wales, Australia, and involved a convenience sample in residential aged care facilities for people with dementia. The authors suggested that ACP is not limited to planning for wanted or unwanted medical treatments towards the end of life but can be expanded to the achievement of 'gerotranscendence'. Gerotranscendence is explained as how the older person continues to realise the 'essence of their being' as they plan and approach the end of their lives (Jeong, *et al,* 2012:159) and how this should be

facilitated in long term care settings. The need for all professionals to pay closer attention to a person's lifetime of values, beliefs, goals and decision making processes is cited as being essential to provide the best possible care for people with advanced dementia at the end of life. The study provides some insight into how spiritual care can be included in care regimes but the lack of studies does not provide specific guidance on how to improve practice.

2.3.4 Summary of Good Death/Bad Death

The limited studies suggest that pain is not often associated with the person with advanced dementia and is often difficult to identify and manage. The person with dementia may not articulate that they have pain but may present with other behaviours, such as agitation, which may be more difficult to interpret and explain. The person may also not present with psychological distress that can be observed visually, particularly in the last few months or weeks as communication diminishes. This would suggest that the social nature of dying with dementia is influenced by the attitudes of staff towards care and the interpretation of suffering. The potential for under or over reporting of symptoms from proxies or care staff should be a consideration and is therefore a limitation from current studies (Casey, *et al.* 2011; Sloane, *et al.* 2008; Brandt, *et al.* 2005).

The LCP (Ellershaw and Murphy, 2011) document has outcomes that can be measured and potential to improve the consistency of care and symptom control for people dying in the last few hours/days of life. Further evaluation of palliative care interventions is required to ensure transferability to people with advanced dementia who are at the end of life.

Due to the nature of the disease trajectory and the unpredictable nature of the disease it is difficult for clinicians to identify when the dying phase commences. Moving towards a collaborative consensus of opinion between all those involved in the care of the person with dementia may allow for a palliative approach to be developed earlier in their disease trajectory. The use of prognostic indicators and care pathways may provide opportunities to guide professionals on when to initiate and deliver palliative care to people with advanced dementia. It is difficult to record what constitutes a 'good death' for people with dementia as little is known about the dying phase. However certain key issues are reported which included being 'pain free', 'dying in preferred place', 'comfort care' and the 'avoidance of inappropriate investigations and interventions'. Spirituality was also not addressed consistently or sometimes not at all in the end of life care for people with dementia but this is difficult to measure in practice and may be subject to interpretation by the health professional. Communication difficulties and lack of responsiveness in the later stages of the disease may be interpreted by health and social care professionals and carers as the 'real self' of the person who has disappeared and so spiritual care is not applicable. The need for all professionals to pay closer attention to a person's lifetime of values, beliefs, goals and decision making processes is cited as being essential in order to provide the best possible care.

The 'good enough death' or the 'avoidance of a bad death' may be the more realistic goal, but how this is achieved is open to interpretation by the 'sufferer' and the 'observer (nurse, doctor or carer)' and may add to the difficulties associated with continuity and consistency of care and treatment.

The Preferred Place of Care (PCC) document is a patient held record promoted by the End of Life Care Strategy (DH, 2008) as an ACP to promote the difficult discussions about what a person's preferences, with life limiting illness, may be for the end of life. If the 'good death' is an individual ideal, then it makes good sense to try and record and/or predict what people, particularly those with cognitive loss, may want for their end of life care. However research suggests that PPC or ACP is a relatively new concept and has limited impact on end of life care in life limiting disease (Preston, *et al.* 2011) other than cancer. This suggests that if health and social care professionals want to meet patient's expectations of a 'good death' then an increased awareness of how to facilitate this is required.

2.4 The Role of Advance Care Planning in Palliative Care

In chapter one advance care planning was described by the World Health Organisation (2011:41) as a 'discussion about preferences of future care between an individual and a care provider in anticipation of future deterioration'. In the UK, the Department of Health (2007:4) also clarified ACP as 'a process of discussion between an individual and their care providers irrespective of discipline ... which takes place in the context of an anticipated deterioration in the individual's condition in the future with an attendant loss of capacity to make decisions and/or ability to communicate wishes to others'.

ACP has been studied in nursing homes for older people with and without dementia. Studies relating to older people without dementia have recognised that ACP discussions can have a positive influence for residents and their family caregivers.

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However studies also indicate that reluctance from residents, staff and family caregivers can inhibit ACP discussions and need further research (Stewart, *et al.* 2011; Karel, *et al.* 2007). A study in Swedish nursing homes for older people by Dwyer, *et al.*(2010) found that it was not routine for nursing staff to discuss death, dying or end of life care wishes with residents. There was a lack of attention to the older person's thoughts and wishes on death and dying, even for those who had been resident for up to two years. A knowledge and understanding of older people's attitudes towards ACP can be useful and can inform health and social care staff who facilitate ACP for people with dementia who wish to introduce ACP at a much earlier stage in the disease trajectory.

This part of the literature review examined the available research relating to the ACP process and proxy decision making by family caregivers on behalf of people with dementia at the end of life. The studies identified in this part of the chapter were generally small scale studies and were often limited to specific cohorts and were not representative of the larger populations (Samsi and Manthorpe, 2011; Karel, *et al.* 2007; Dobalian, 2006; Lacy, 2006; Engel, et al. 2006).

For opportunities to represent as clearly as possible the wishes of the dying person with dementia, rather than the professionals or service assumptions, it is essential to involve the family caregiver. Froggatt, *et al.* (2009) suggested that in care homes ACP is dependent upon intrinsic and extrinsic factors relating to the implementation of ACP which includes; resident participation, family and staff attitudes, structural, legal, moral and barriers to implementing issues. This part of the literature is directly relevant to my own study as it explores the relevance of ACP for people with

advanced dementia and the role and contribution of proxy decision makers such as family caregivers.

Pearlman, *et al.* (2000) interviewed 342 participants from seven groups of people in Washington, USA, with life limiting conditions to examine patients' life sustaining treatment preferences to facilitate ACP discussions and surrogate decision making. Participants were asked to consider preferences for antibiotics, aggressive life sustaining interventions, tube feeding and three hypothetical health states representing severe dementia, coma and severe stroke. Results suggest that preferences for life sustaining treatment across situations are influenced by anticipated functional outcomes and that brief interventions, as well as those required for the remainder of the person's life, should be part of ACP discussions. Participants were also much more likely to forgo treatment in the hypothetical states that described decisional incapacity than in their current decisional competent health state. The group was described as being mostly white and better educated than the general population which suggests that the reliability of the results may not be transferable to the diversity of the whole population. The research is useful in that it highlights the willingness to discuss the following study but the use of hypothetical scenarios may be inconclusive in replicating or generalising the study to other groups and across different settings and cultures to predict the accuracy of preferences.

A study by Moorman and Carr (2008) examined the extent to which older adults accurately report their spouses' treatment preferences in the hypothetical scenarios of terminal illness and physical pain, and terminal illness and severe cognitive decline. Using the data from 2,750 married couples in 2004, the results suggested that where

couples had discussed their end of life preferences were more likely to accurately report the spouses' preference than to be uncertain. This adds to the evidence that suggests early discussions benefit the accuracy of surrogates to make the appropriate decision to best reflect the wishes of their relatives. Barrio-Cantalejo, *et al.* (2009) randomised trial involved two intervention groups and a control group. The study described the accuracy of interpretations of advance directives of patients' preferences. The Andalusian Advance Directive Form (AADF) was used to compare the accuracy of proxies' predications about patients' preferences. The AADF is described as an official document used to draw up advance directives in Andulasia. The study was conducted during 2005-2007 and 386 participants were recruited from six primary care centres and one nursing home within Granada, Spain. Participants were selected randomly but had to have the capacity to make decisions. Participants were asked to identify a proxy and were randomly assigned to one of the study groups. Comparisons were made between the patient's wishes and the proxies' identification of what they felt the patient would indicate within an advance care plan. Results suggested that where a discussion had taken place between the proxy and the patient the results were more favourable in predicting advance care planning requests. However despite this conclusion the results in both control and AADF groups' proxies predicted correctly in less than 60% of cases, despite patients expressing high confidence in their proxies to make the correct decisions. Limitations of the study cited issues relating to the AADF improvements, the lack of experience of being a proxy, the low to medium educational level of the participants and the limited range of medical scenarios used to obtain feedback, could all have influenced the results.

Despite ACP documentation being promoted there remains little evidence within the literature that it is widely used in practice as the following study demonstrates. Yung, *et al.* (2010) assessed the flow of ACP information from patients to medical records in a community sample of older adults to better understand why ACP is not more successful. The study analysed the data collected from two previous quality of care evaluations (ACOVE -1, ACOVE -2) which focused on people aged over 65 years in community medical practices in the USA. ACOVE-1 included data from 245 patients in 1998-1999, ACOVE-2 included data from 566 patients in 2002-2003. The study concluded that despite early discussions on treatment preferences and choices with physicians there was very little evidence to suggest that this is documented officially in any medical records. Despite the willingness to discuss such issues, patients generally did not regularly discuss end of life issues with their care providers. The reasons why the preferences and choices were not documented are uncertain.

There would appear to be a readiness to discuss end of life issues amongst older people within these limited studies. However the previous studies suggest that a more structured approach to discussions and documentation could reduce problems associated with advance care planning.

2.4.1 The Role of Advance Care Planning in Palliative Care for People with Dementia

Hughes, *et al.* (2007) suggested that palliative care for people with dementia is not just a matter of terminal care but about living well until the point of death. Assessing a person's quality of life in dementia is particularly problematic for practitioners due to its subjectivity and interpretation (Corner and Hughes, 2007). Difficult decisions

during the advanced stage of the disease are often related to the use of tube feeding, hospitalisation and the identification and use of proxies.

The following study by Moss (2002b) identified that despite the recognition of the palliative care needs of people with dementia, staff were not always able to meet these needs. Moss, *et al.* (2002b) completed a national survey of 400 nursing homes in the USA to explore the terminal care for residents with Alzheimer's disease. In the survey 44% of residents who died within the study period (1998) had dementia. Results indicated that 93% of nursing homes think that residents with dementia who are dying have special needs. However 53% of nursing homes agreed that they have to make difficult decisions about the terminal care for residents in the absence of advance directives and 55% of nursing homes identified pain as being problematic in the resident with end stage dementia who is dying. Researchers suggest that although nursing home staff expressed an awareness of the care needs for people with dementia, advance planning may reduce the burden of decisions regarding appropriate interventions. Further staff training and education was seen as being essential particularly in the issue of pain recognition and management in the resident with dementia. There may also be additional variables which exist across different settings that could contribute to the difficulties associated with delivery, such as staffing levels, access to medical staff and additional resources and equipment.

Preliminary qualitative work with the principal carers of 20 patients with severe dementia and 21 healthcare professionals in Sampson, *et al.*'s (2008) study revealed five main themes from the data; illness awareness, communication, pain awareness, attitudes towards end of life treatments/quality of life and hospitalisation. The study's

aim was to improve the quality of end of life care received by people with advanced

dementia by intervening at the point when patients have an unplanned admission to an

acute General Hospital. Results indicated that the majority of relatives said they

wanted more information about the symptoms of advanced dementia but decisions on

resuscitation could be influenced by religion, patient's quality of life and anxiety

about making such decisions. Physicians thought resuscitating patients with

advanced dementia was unacceptable. Attitudes towards tube feeding were varied.

The authors conclude that communication and ACP should be at the centre of an

intervention attempting to improve end of life care for this patient group, especially

providing relatives with adequate information regarding the nature of dementia and its

likely progression.

Issues relating to religious beliefs and the legal standing of some advance directives

were more likely to cause difference of opinion with relatives and physicians

respectively. Rurup, *et al.* (2006) investigated the factors that could influence

attitudes towards medical end of life care decisions concerning patients with dementia

from the perspectives of physicians, nurses and relatives. Three regions within the

Netherlands were selected and 70 nursing homes were invited to participate. Thirty

nine nursing homes agreed to participate and data was collected in 2000. Seventy

five physicians, 178 nurses and 136 relatives were involved in the study. Fifteen

statements about artificial nutrition and hydration (ANH), advance directives,

hastening death, self determination and euthanasia were used to stimulate discussion

and understanding between all parties within a nursing home environment. In 60-

65% of all responses there was general agreement between physicians, nurses and

relatives. The authors conclude that physicians have great influence on end of life

decisions and therefore should encourage open and honest discussions on end of life care within nursing homes. Further work is required to understand if the findings in this study impacted upon the quality of the dying resident.

Advance care plans can take different forms. The following study (Dobalian, 2006) used data completed in 1996 (n= 5708) and three types of advance care plans were examined. Dobalian's (2006) retrospective cohort study assessed clinical, demographic, facility and regional factors associated with documented do-not-resuscitate (DNR) orders, feeding/medication/other treatments (FMT) restrictions and living wills among nursing facility residents; 53% (n= 3105) of the residents had one or more advance care plans. A summary of the evidence suggested that DNR orders have been found to be more prevalent among older residents. Residents in poorer health were more likely to have advance care plans. Residents with dementia were less likely to have living wills. The study suggests that there is a need to improve the uptake of advance care plans to ensure as much as possible that the needs of the residents are considered and appropriate care is offered and delivered, especially when being admitted to hospital.

In a study undertaken by Lacy (2006), 138 nursing home social service staff across New York responded to a survey about advance directives, medical interventions and comfort levels involving withholding and withdrawing treatment for people with dementia. Results indicated that although advance directives were generally in use, there were some concerns and a mixed response rate over the withdrawal and withholding of treatment and hospitalisation for people with dementia. The author concluded that a more coordinated approach to palliative care is needed, and that

social service staff would benefit from further ongoing educational opportunities on palliative care practice, which includes ethical decisions at the end of life.

There does not appear to be conclusive proof that ACP contributes to the quality of care, however studies do confirm the need to coordinate palliative care interventions and involve family caregivers to potentially maximise comfort care at the end of life. The importance of communication with family caregivers is highlighted in the following study.

Time spent discussing advance directives with the healthcare providers increased the healthcare proxies/family members (HCP) satisfaction as did care in a specialist dementia unit. Engel, *et al.*'s (2006) study attempted to identify factors associated with the satisfaction of formally designated HCP with the care provided to 148 persons with advanced dementia in 13 nursing homes in Boston, USA during 2003-2005. Using a an existing validated 10 item survey tool, the Satisfaction With Care at the end of life in Dementia (SWC-EOLD) quantifies satisfaction with care in advanced dementia during the prior 90 days. Comfort care such as pain management was associated with higher satisfaction. The authors suggested that spending more time discussing advance directives, improving comfort care, less use of feeding tubes and management in specialist dementia units are potential interventions to improve satisfaction. Limitations included the lack of a diversity of participants (all were almost white) and that detailed information was not available about the advance planning process.

Goodwin and Waters (2009) suggested that communication needs to be improved between professionals, carers, and where possible with patients, to discuss ACP in a much more structured and routine way. Goodwin and Waters (2009) explored the opinions of people with advanced dementia, their families and professional caregivers in four hospital wards and three care homes in the UK, on promoting well-being during the last months of life and good terminal care. Interviews were undertaken with 12 triads, one patient, one family carer and one professional carer. The research challenges the idea that people even with advanced dementia cannot contribute to end of life care discussions and cite some examples of how, albeit limited, the patient had appeared to understand the question without any undue distress or anxiety. There were examples of how family carers appeared to have some awareness of their relatives' feeling about death and dying based on their previous lifestyles and opinions, but there was a lack of firm planning and discussion. Although not conclusive and transferable to other settings, the research does suggest the potential contribution of residents and family caregivers to ACP. A lack of overall excellence in dementia care was one of the concluding remarks.

Dementia was discussed as a condition which might be a reason for the participants to make advance plans as there was little chance of recovery and they were likely to lose capacity. Samsi and Manthorpe (2011) explored the attitudes of a diverse sample of 37 self declared, well, older people living in the community in London, England about their views on drawing up statements of wishes and documenting their decision-making preferences. Interviews with the subjects revealed four main themes; individual inclination to plan, types of plans, reasons for planning, and support with planning. A majority of participants reported their disinclination to plan

as they felt their spouses or children who knew them best would be able to make decisions on their behalf. The Mental Capacity Act (MCA, 2005) was not widely understood as a tool for assisting in the production of advance plans. The authors concluded that planning appears to be largely driven by individual disposition, and that there is a need for information on the benefits and support available for the completion of advance care plans. The small sample size may indicate the results may not be generalisable to other populations and settings.

A study from Yeun-Sim Jeong, *et al.* (2011) studied the experiences of 13 registered nurses undertaking ACP in a residential care setting in Australia. The authors examined the factors which enhance or inhibit the experience of registered nurses when facilitating ACP. The registered nurses generally found these uncomfortable, which suggested that meaningful discussions with older people and their families to maximise participation in advance care planning, was not promoted. Structure and guidance may provide registered nurses with the skills and confidence to promote such discussions. This is particularly important to ensure that the culture within the setting promotes a palliative care approach when necessary and this would confirm the need to identify when residents enter the dying phase. Various prerequisites were required for successful implementation in this Australian study which may not be generalisable elsewhere.

Non competent patients, although excluded in the following study, required advance planning needs to be incorporated into routine care so that patients were given the opportunity to discuss end of life care prior to becoming non competent. Detering, *et al.*'s (2010) Australian RCT studied the impact of ACP in elderly patients within a

university hospital in Melborne. A group of 309 inpatients within cardiology or respiratory medicine, described as legally competent, aged 80 years or more, were followed for six months or until death. This group was recognised as being representative of the 51% of all the deaths within the hospital. Patients were assigned to either the control group or intervention group. Within the intervention group, each patient received formal ACP information from a trained facilitator using the 'Respecting Patients Choices Model'. This is described by the authors as involving a coordinated approach to ACP where patients document their wishes about end of life care. ACP was received by 125 patients. Within the document patients were encouraged to appoint a surrogate and document their wishes about end of life care including treatment, interventions and resuscitation preferences. Results indicated that ACP has potential to influence end of life care providing this is undertaken by trained facilitators, patient centred discussions, and involvement of family, accurate documentation and the education of doctors. The study found that focusing on goals of care, rather than medical care which may be poorly understood, was more useful for patients when making ACP decisions. A comparison of usual routine care and an accounting of costs for the interventions may be useful for future studies to consider different settings and cultures.

A study from Sampson, *et al.* (2010) designed and piloted a palliative care and ACP intervention within an acute hospital in UK for people in an advanced stage of dementia. Thirty three patients and carers were recruited but despite care planning discussions with carers only seven carers wrote an ACP despite 'intensive support' from a nurse specialist and it is suggested that more research is needed to examine why this reluctance exists. Facilitating ACP discussions much earlier in the disease,

before capacity is lost was viewed as being beneficial. Although a limited study this does contribute to the debate on the value of initiating ACP earlier in the disease trajectory.

Advance Directives (AD) for euthanasia are legally recognised in law in the Netherlands (Termination of Life on Request and Assisted Suicide 2002). In a large scale study involving 434 physicians, de Boer, *et al.* (2011) found that advanced directives for euthanasia were rarely adhered to, citing the lack of current capacity of the person with dementia to give directions, despite the previously completed AD. However the AD did provide a supportive role for physicians to set limitations on life-sustaining treatment. Eight relatives of people with dementia were also interviewed as part of this study. Acting on the AD for euthanasia was a difficult task for relatives who often felt more comfortable forgoing life prolonging treatment for palliative options which included palliative sedation. However they were not always content with this decision as 'dying' took longer that they had anticipated.

These limited and inconclusive studies suggest that ACP can have the potential to influence the end of life care for older people with chronic disease, including dementia. However it is generally agreed that these discussions should be facilitated with the person themselves at a much earlier stage in the disease, so that the decisions at end of life can best represent the person's end of life care wishes. However it would also appear, within some of the studies, where previously informal discussions had taken place, relatives were able to represent the views with some accuracy. This has relevance to my study in that it confirms the potential contribution that family caregivers in their role as proxy decision makers.

2.5 The Role of Proxy End of Life Decision Making of Family Caregivers of People with Advanced Dementia.

Although more common in the USA and the Netherlands, advance directives or advance care plans are not widespread in the UK. Physicians in the NHS are encouraged to consider such options and when they may be considered for people with a chronic condition as part of the end of life care strategy (Conroy, 2009; DH, 2008). The point at which an ACP becomes imperative to the person with dementia often involves a recognition of the terminal phase of the disease, which as referred to earlier in this work that can be problematic for health professionals. Difficult decisions often relate to the continuation or withdrawal of medical treatment and interventions such as medication, feeding tubes, treatment for newly diagnosed conditions and the appropriateness of other investigations such as blood tests (Baldwin, 2004), which may not be appropriate to the dying person. Family caregivers need guidance and support to deal with difficult emotions and to understand the disease trajectory (Forbes, *et al.* 2000).

2.5.1 Personal Experiences of Family Caregivers of People with Dementia

Family members and other informal carers often experience practical, psychological and economic strain as a consequence of their caring role, which could have lasted for several years and often involves the stress of making decisions for their relatives (Stirling, *et al.* 2010; Campbell, *et al.* 2008; Wackerbath, 1999; Almberg, *et al.* 1997). Several studies have attempted to capture the psychological distress that some family caregivers experience from diagnosis to end of life (Kiely, *et al.* 2008; Papastavrou, *et al.* 2007 Robinson, *et al.* 2005; Galvin, *et al.* 2005; Albinson and Strang, 2003a; Aggarwal, *et al.* 2003a). The studies are often qualitative and involve a small sample

of participants. Results suggest that caregivers are highly burdened due to stressful caregiving situations which do not alter even when the person is admitted to long term care (Ablitt, *et al.* 2009; Papastavrou, *et al.* 2007; Aggarwal, *et al.* 2003). Once in long term care the caregivers are usually anxious about their relative's happiness and their deteriorating relationship and this can contribute to family-staff conflict due to confusion over their role (Aggarwal *et al.* 2003, Albinson and Strang, 2003a, 2003b). Where structured interventions have been introduced to reduce this family-staff conflict, studies have demonstrated that there is potential to be of benefit to the resident with dementia and the family-staff relationship (Kellett, *et al.* 2010; Finnema, *et al.* 2001). Caregivers of persons with dementia go through anticipatory grief at different stages from initial diagnosis to death (Lindstrom, *et al.* 2011a).

Within the available literature there is very limited evidence of how family caregivers engage in ACP discussions which is directly relevant to my study within this thesis. The following study is an example of how health professionals can facilitate communication with family caregivers.

Kellet, *et al.'s* (2010) small pilot study in Brisbane, Australia, examined the use of life stories and biographies of residents as a means of connecting family and staff to people with dementia. Family Biography Workshops facilitated the 'engagement of staff, family members and friends of the person with dementia in the co-constructions of the lives of people with dementia in residential care' (Kellet, *et al,* 2010: 1708). Despite being a small study, early indications suggested that the Family Biography Workshops improved relationships and staff began to appreciate the person with dementia in the context of their family and friends. The gradual disappearance of the

person with dementia and loss of communication is stressful and most studies suggest that health and social care professionals need to support family caregivers in their experiences of the dementia journey. Specific training is needed so health and social care professionals can understand and manage the feelings of family caregivers (Papastavrou, *et al.* 2007). It is inevitable that, due to the sensitive content of the ACP discussions for end of life care, this can contribute to the physical and psychological burdens endured by the family caregivers. The study suggested that communication can be promoted in creative ways within the care home setting and although limited to this particular setting it does offer some insight to health professionals on how to engage family caregivers in discussions.

2.5.2 Proxy End of Life Decision Making of Family Caregivers

Hughes and Dove (2004) suggested that in advanced dementia, end of life care decisions require attention to broader ethical principles, which include a respect for the person's autonomy in the midst of competing concerns. This includes protecting from harm, defending their best interests and openness and truthfulness, suggesting the relationship and current reality of the person with dementia is acknowledged. The loss of relationships in people dying of cancer has been researched in Lawton's work (Lawton, 2000) and is particularly relevant to persons with dementia as the loss of self and ability to maintain relationships has occurred sometimes several years prior to death (Corner and Hughes, 2006; Sandman, 2005).

According to Woods (2007) health professionals often assume that the family has a role in determining a person's best interest at the end of life. Woods (2007) argues that professionals make assumptions concerning the relationship with the dying

person which may or may not be accurate, and this often represents another layer of complexity in the decision making within palliative care. The person with advanced dementia is not in a position to identify their end of life care choices or their choice of family advocate and so the health professional must ensure that they balance decisions in the best interest of the patient, despite competing interests of different individuals. Kiely, *et al.* (2008) studied the loss experienced by family members of dementia patients before their actual death. The study included 315 nursing home residents with advanced dementia and their health care proxies (HCP) in Boston USA. 'Separation distress' as a result of loss of the person due to the degenerative disease trajectory, was the most common 'pre death grief' symptom, suggesting family caregivers need support and would benefit from early interventions to reduce distress. Knowledgeable health care professionals in palliative care options and the process relating to death and dying are essential in supporting family members when making difficult decisions. This part of the literature review is relevant to my study in that is explores the nature and difficulties of undertaking the role of proxy decision making. The studies are generally small scale studies which may not be transferable across different settings and cultures. However there is some limited evidence of the contribution of family caregivers to ACP discussion and completion.

Preserving dignity and promoting comfort were described by participants in the following study as desirable but broad concepts and they were unable to incorporate specific goals into treatment plans (Forbes, *et al.* 2000). Participants were also unable to describe the disease trajectory of the disease and dying process and did not envisage their relative's dementia condition as terminal. Forbes, *et al.* (2000) qualitative inquiry involved four focus groups in four selected nursing homes in a

Midwestern American city based on their racial and economic diversity. The purpose of the study was to describe families' decision making process regarding treatments for nursing home residents with moderate to severe dementia. Twenty-eight family members participated in the focus groups. Five themes were identified from the study results which indicated the experience of decision making, emotional effect, insult-to-life story, two faces of death (tragedy versus blessing) and the values and goals regarding end of life treatment. Many of the residents had advance directives in the event of a terminal illness but family members were unclear about what a terminal illness was. The focus group had the effect of challenging the participants into thinking about what decision could be or would be made at the end of life and this suggested that a lack of preparedness prior to this. It should be considered that focus group members can influence each other by responding to ideas and comments during the discussion. The authors described the family members as travelling a 'long, arduous and unwelcomed journey' (Forbes, *et al*, 2000:256) but that death was not part of the day-to-day experience of the family members within the focus groups. The study concluded that an important issue in ACP is that communication with a consistent provider could allow for the transition of medical information into an understanding of the disease trajectory and reduce confusion, guilt and burden.

Responsibility, existential isolation, meaning and death were the focus of the interviews with twenty family members whose relatives had moderate or severe dementia and were currently residing in one of two nursing homes or attending a day centre. Albinson and Strang (2003a) Swedish study's aim was to increase understanding of existential questions that family members have as they are related to the diagnosis of dementia. This study, although a small sample, identified the

devastating emotional context that family members witness as the person with dementia deteriorates. Not being able to communicate, being a parent to your own parent, having no one to talk through existential issues was common amongst the participants. Death and dying were avoided topics for some of the participants and they did not necessarily see dementia as an illness that would cause death. Existential issues concerning life and death had not routinely been discussed with staff, and family members did not have any expectations that staff would address these issues. The authors concluded that it was important to acknowledge the distress of the family members at the 'gradual disappearance' (Albinson and Strang 2003a:233) of their relative with dementia. Albinson and Strang (2003a) suggest that allowing families to verbalise their existential thoughts and supporting them in their existential crisis, could be of great importance to enable them to cope and adjust in the future.

Although ACP not directly referred to in the following study, it did identify what might influence end of life care discussions, despite the difference in cultures. Wakunami, *et al.* (2009) study in Okinawa, Japan examined family's acceptance of near death in elderly patients with severe brain damage from a variety of causes including dementia. As part of this study ten family members who had made important medical decisions and/or care for their aged relatives were recruited and interviewed during 2000-2002. The sample size was small and used focus groups. Focus groups may have influenced participants to adopt consistent views and therefore may not be generalisable to different settings and cultures. The interview questions were concerned with what influenced their decision making, for example, age of patients, information accuracy, communication between health professionals and the family caregiver and other opinions which may influence them. Analysis

yielded eleven categories; family affection for continued survival, vacillation of desire for death and dignity, family members' hierarchy, awareness that others may make different decisions, family members' discussion overcoming discordance, satisfaction with the physician's decision, impressions of life sustaining measures, entrusting important decisions to hospital physicians, significance of family members' previous experiences, patient's age and duration of medical treatment. The conceptual model which was generated suggested that relatives at different stages move from a desire to prolong life, to the acceptance of death with dignity. Knowledge of this conceptual framework may guide other health professionals to examine when and how discussions on care should be introduced, particularly if no advance discussions had taken place. The study also focused on the physical aspects and the authors accept that psychosocial, ethnicity and culture could be the focus of future studies. The study results cannot be generalised but rather the aim was to develop an understanding of the acceptance amongst families of near death in an elderly patient.

A qualitative study by Elliott, *et al.* (2009) with eight focus groups in 2003 included 39 family members of severely impaired nursing home residents in Minnesota, USA. The aim of the study was to describe and understand the ethical thinking used in end of life decision-making by family surrogates. Focus group discussions allowed the family members to describe their experience of undertaking this role and it was reported that it was as a result of the inevitable decline of their relative. They also only made decisions from their own experience and what they interpreted as being meaningful to their relative and their story. Decisions were generally discussed in terms of best interests, which included alleviating suffering and declining aggressive

or intrusive medical interventions. The families attempted, where possible, to represent the autonomy of their relatives but this was not always easy to interpret unless wishes in the form of advance directives had been discussed. Eventually the use of beneficence guided their decisions although the timing of this was different for each family. This is possibly the most relevant to my study in that it explores the experience of decision making, however the difficulties associated with focus group formats and how this may or may not contribute to ACP was not included.

Givens, *et al.* (2009) study describes the medical decisions confronting health care proxies of nursing home residents with advanced dementia. Within the Boston (USA) area 323 nursing home residents with advanced dementia and their surrogates were recruited from 22 sites. Baseline and follow up interviews were conducted as part of the data collection over a maximum period of 18 months. If the resident died within this time an assessment was conducted 14 days after death. Feeding problems (27%), infectious episodes (20%) and pain (13%) were common clinical complications that required decisions from proxies. Results also indicated that satisfaction with the decision making activity was lower than the satisfaction with the decision itself, indicating that support from health professionals is important to support proxies in their decision making process. Satisfaction with decision was also higher if the resident was on a specialised dementia unit. The decision making was associated with acute episodes and not ACP. The study highlights the range of decision that family caregivers may need to consider in advance for their relative with advanced dementia.

A model was developed to describe how surrogates developed an understanding of what their relatives' preferences may be for care. Black, *et al.* (2009) studied how surrogate decision makers for dementia patients develop an understanding of patient preferences about care and patient wishes. A purposeful sample of surrogates in the CareAD study was recruited. The CareAD project was a larger study involving three nursing homes in Maryland (USA) which met hospice criteria for dementia. The CareAD study collected data using multiple methods to document the management of patients with chronic and acute health problems during their final months of life and also the experience of their surrogate decision makers (Black, *et al.* 2006). Thirty five surrogates were interviewed (during 2003-2005) once every three to five months, which included a final interview after the patient's death or at the end of the study. The model identified included factors that influenced whether an individual expressed their preferences for care, sources of information from which surrogates obtained their understanding of patient's wishes and what surrogates understood patient's wishes for care to be. Results indicate that where discussion took place these were sometimes previously translated into advance directives (59%) and surrogates were able to extract specific information and guidance relating to treatments and interventions. However barriers to decision making included a lack of discussion with the patient or that the patient's cognitive impairments did not allow for such discussions. Eleven surrogates had no knowledge of patient's wishes, were uncertain and had no information. The authors conclude that 'advance care planning cannot relieve all the burdens that surrogates bear when making care decisions, it may provide some comfort if their decisions are in keeping with the patients prior wishes' (Black, *et al.* 2009:648). The conclusions also confirm the limited evidence available to fully acknowledge the role of ACP. This is useful to my study in that it highlights

the complex nature of ACP especially if the family caregiver had no knowledge of the person's previous prior wishes.

There is insufficient evidence to identify a 'best' approach to ACP for people with dementia and family caregivers are often making decisions based on insufficient knowledge and support which implies a serious lack of support and protection for the vulnerable person with advanced dementia. There is also limited evidence of the experience of family caregivers when making end of life care decisions for people with advanced dementia. It is also not clear how these decisions impact upon their own grief, decision making behaviour and how these are resolved prior to, or after the death of their relative. Other past and present research studies confirm the need for a consistent approach to the continued education and training of all generalist care staff involved in palliative care for older people with or without advanced dementia

2.6 Summary of Chapter Two

The majority of the literature included in this review was qualitative and was from outside the UK. The studies reviewed have pointed to barriers that affect the recognition of needs and delivery of palliative care needs for people with dementia. There is emerging evidence in favour of ACP, however it is yet to be established if ACP has a positive effect on the quality of end of life care for people with and without dementia. ACP is promoted in the UK End of Life Care Strategy (DH, 2008) but it has been found that it is difficult of engage family caregivers in formulating plans for people with advanced dementia (Sampson, 2010). The reason for not choosing to participate in ACP is generally described as a complex activity, and an

assumption that there is a general unwillingness to make decisions about hypothetical care.

Much of the current literature is limited to clinical articles and focuses on the acknowledgement that dementia is worthy of palliative care, and that ACP can provide an opportunity to influence best practice. However most of the studies involving family caregivers aim to identify the motives or rationale of the decisions / actions made by the family caregivers (ACP not always referred to as a structured document) at the advanced stage of the disease rather than examine the experiences of the family caregiver of being asked to document decisions in an ACP prior to the death of their relative which is directly relevant to my study.

The literature does suggests that there is a lack of agreement and acknowledgement that people with dementia were dying and this appears to be influential when planning and delivering palliative care. This lack of a coordinated philosophy was not uncommon (Gott, *et al.* 2011; Houttekier *et al.* 2010; Mitchel, *et al.* 2009; Mitchel, *et al.* 2007a) and may be associated with the difficulties associated with prognostication (Mitchel, *et al.* 2007b; Mitchel, *et al.* 2004b; Lloyd-Williams and Payne, 2002). Further studies could focus in more depth as to how palliative care could be introduced effectively into dementia care.

Hospitalisation was not an uncommon practice, particularly from non specialist dementia units which also suggests a lack of knowledge about the disease trajectory and when to initiate a palliative care approach (Mitchel, *et al.* 2007b). Difficulties with prognostication are also cited for the lack of hospice referral during the dying

phase in the US due to the rigid protocols for access (Mitchel, *et al.* 2007b). Where clinical guidelines have been identified this does suggests that there are potentially clinical indicators that could alert the health professional to acknowledge the person is moving towards the dying phase (Formiga, *et al.* 2007; van der Steen, 2010). The literature highlights the usefulness of clinical indicators / guidance but this needs further evaluation. Currently there is limited evidence that these impact upon the timely implementation of palliative care for people with dementia.

A lack of confidence or anxiety within the care setting staff to make appropriate decisions and adequately manage symptoms of the dying person was associated with medical interventions which included aggressive management and treatment of symptoms at the end of life. Often these decisions were based on what the clinicians think may be beneficial or detrimental for people with advanced dementia (Regnard and Huntley, 2006; Parsons, *et al.* 2010). Clearly more research is needed into the role of the physician in early implementation of palliative care and how a multi-disciplinary approach could potentially influence this. Where interventions have been evaluated (McClelland *et al.* 2008) the findings and recommendations for good practice may not be transferable across settings. Intervention strategies require resources and it has already been well established that people with dementia have historically been a marginalised and disadvantaged group (WHO, 2012).

Spiritual care was a neglected issue for people with dementia. Spiritual care was associated with dignity and a respect for the person's past and current existence. Although the studies suggest this is an issue that is acknowledged by care professionals, it is not given sufficient attention as part of comfort care and that a lack

of communication and awareness from the patient/resident contributes to this (Fargeau, *et al.* 2010; Lawrence, 2007; Dinning, 2006; Brandt *et al.* 2005; Mast, *et al.* 2004). Further investigation is needed to examine the specific needs of people with dementia in relation to end of life care.

ACP is not widespread in the UK and therefore is it difficult to evaluate the impact on end of life care for people with dementia. There is some suggestion from the literature that ACP can reduce some of the burden of decisions regarding end of life interventions and care (Ashton, et al. 2009; McClelland, et al. 2008; Engel, *et al.* 2006). Most of the findings have limited generalisability because of the dearth of available evidence. It is suggested that concerns over the legal standing of such plans and the complexity and range of different forms (Rurup, *et al.* 2006; Dobalian, 2006) can contribute to the lack of implementation in care settings. Care setting staff and other health professionals should engage in more communication with people in their care and would benefit from further education and training in the potential use of ACP (Samsi and Manthorpe, 2011; Goodwin and Waters, 2009; Lacy, 2006). Guidance from the National End of Life Care Programme (DH, 2011a) and the General Medical Council (GMC, 2009) has been published to guide and support clinicians on ACP. The guidance includes clarification on the importance of assessing a person's capacity, in relation to the Mental Capacity Act 2005 (MCA, 2005) to make decisions about their care. It is also acknowledged within the literature that there is more to ACP than planning medical interventions and that comfort care needs to be explored and emphasised within discussions (Detering, *et al.* 2010). Despite the limitations of the evidence the studies highlight that ACP warrants

consideration and could be used to inform decisions relating to the end of life care needs for people with dementia.

End of life decisions for people with advanced dementia are reported as often being difficult for families but they appear to attempt to make appropriate and justified decisions within the context of the person's life story (person centred) which is also confirmed in other studies (Goodwin and Waters, 2009; Black, *et al.* 2009; Moorman and Carr, 2008; Baldwin, 2004). Anticipatory grief and isolation has been identified and acknowledged due to the often lengthy disease trajectory of dementia and the loss of the person due to communication and memory loss (Lindstrom, *et al.* 2011a) as it becomes difficult to maintain and sustain relationships (Lawton, 2000). These existential issues include experiences and feelings, which are not often addressed and managed by care staff (Papastavrou, *et al.* 2007) and may impact upon appropriate end of life decision making. Studies also suggest that families struggle to represent the wishes of their relative and where previous discussions have taken place this can be beneficial (Elliot, *et al.* 2009; Black, *et al.* 2009).

In general terms, current studies are limited so it is difficult to justify any general themes to inform practice. Culture may also have influenced the findings of specific studies. However, it is suggested that in most studies ACP discussions are confirmed as being useful, with family care givers to guide appropriate care and treatment at the end of life. What is clear is that family caregivers struggle to 'do the right thing' and often other existential issues impact upon their readiness to participate in end of life discussions. It is not clear how these issues impact upon their own grief, decision making behaviour and how these are resolved, prior to or after the death of their

relative. The experience of separation distress and role conflict has implications for health and social care practitioners who wish to engage family caregivers in ACP discussions and should appreciate the sensitivity and potential additional distress this may cause.

This thesis contributes to the understanding of the experience of undertaking an ACP by family caregivers, who often attempt to represent the person with dementia at the end of life. This study advances knowledge to assist nurses in care homes and in other countries to develop and apply ACP to the benefit of residents and their families and to inform the development of services, care and further research. Recognising and maintaining the importance of promoting a person centred care approach to decision making, which maintains the integrity of people with dementia, and also acknowledging the importance of the relationship of trust and honesty between family caregivers and health professionals, is an essential consideration. This thesis has explored the issues which appear in the studies within this literature review. It also contributes to the understanding of the experience of ACP with family caregivers as representatives for the person with dementia at the end of life who resides in a nursing home, and offers recommendations for improving practice amongst health and social care professionals when undertaking sensitive discussions. This thesis offers a composite case for practice which will include the contributing factors that need to be acknowledged by health and social care professionals when undertaking ACP with family representatives.

Chapter three which follows describes the detailed design and methods of this study which was to gain an understanding of the experiences of ACP by family caregivers

who have cared for a relative with dementia. ACP is a relatively new initiative within the UK and is not yet facilitated sufficiently well for people with and without dementia, therefore, family caregivers are often asked to contribute to the end of life care treatment and options when end of life is imminent. The study also included how the family caregivers' role as proxy decision makers had influenced their own view of dementia, dying, and the ACP process and how palliative care was delivered within a long term setting. The chapter also includes a critical justification on the choice and appropriateness of this qualitative research design. This includes the need to recruit appropriate participants who have experience of ACP, the use of interviews as an appropriate method of data collection to reflect experiences, and how the appropriate selection of data analysis tools enabled this experience of the relatives and carers to be reported. Ethical considerations are also discussed in detail to reflect the handling of sensitive topics relating to end of life care. The respondents in this study were either close family members (spouse, daughter, son, granddaughter, and brother) or part of the extended family (niece) and had been involved in proxy decision making.

Chapter 3: A Study to Explore the Experience of Advance Care Planning amongst Family Caregivers of People with Advanced Dementia.

3.1 Introduction

In chapters one and two, ACP was defined as a process of discussion between an individual and their care providers (DH, 2007). It is described as a planned discussion which often focuses on the perceptions and potential choices of care and treatment that the person, usually with a life limiting illness, has about their future care. However when the person involved has advanced dementia, this discussion, if not undertaken during the earlier stages of the disease, is often between the family caregivers and the care providers, who may act as proxies on behalf of the person (DH, 2007; MCA, 2005). The intention being to reflect, as much as possible, the preferred preferences of end of life care of the person with advanced dementia, based on the knowledge and experience of their family member and/or care provider. The purpose of this study was to gain an understanding of the experiences of family caregivers who have undertaken ACP for a relative who has advanced dementia within a long term care setting within the United Kingdom (UK).

ACP decisions have the potential to influence the end of life care of the person with dementia and so it is worthy of interest to identify how relatives and carers accept and experience this responsibility. It was established in chapter two that, although there is a lack of research relating to the end of life care for people with advanced dementia, decisions such as artificial feeding, pain management and other active medical and nursing interventions are often discussed with family caregivers to achieve a

consensus of opinion on how to act in the best interests of the patient. The design of this research captured the experience of family members as they attempt to provide an insight into what people with advanced dementia, who may be incapable of making informed decisions, have about the choices they would wish to make at the end of their life. What follows is a critical discussion on the choice and appropriateness of this qualitative research design. This includes the need to recruit participants who have experience of ACP, the use of interviews as an appropriate method of data collection to reflect experiences, and how the appropriate selection of data analysis tools enabled this experience of the family caregivers to be reported. Ethical considerations are also discussed in detail to reflect the handling of sensitive topics relating to end of life care.

3.2 Research Question and Study Objectives

Research question

What are the experiences of family caregivers of undertaking ACP on behalf of people with advanced dementia?

Study objectives

- To explore the psychosocial experience of family caregivers when caring for and/or supporting a person with advanced dementia, prior to and during admission within a long term care setting.

- To investigate the role of ACP in the care of people with dementia who are at the end of life from the perspectives of family caregivers within a long term care setting.

- To analyse the experience of family caregivers when undertaking ACP with professional care setting staff within the long term care environment, to inform future skill and knowledge development amongst health care professionals.

- To identify the essential knowledge and communication skills required by care professionals when facilitating ACP with family caregivers of people with advanced dementia that are at the end of life.

3.3 Research Design

A qualitative approach was an appropriate choice for this type of study, as the aim was to identify the experience of family caregivers when undertaking advance ACP with professional care setting staff within the long term care environment. Qualitative research is reported to be value based as it attempts to gain a deeper understanding of the area under investigation (Smith and Bowers-Brown, 2010; von Kardorff, 2004) and to explore the social world of participants and what can be known about it (Flick, 2009). Silverman (2006) suggests that the choice of the different qualitative research methods should depend on the aims of the study and should reflect the diversity of participants recruited to meet the study objectives. Qualitative research is considered to be more involved than other research strategies, often in response to guided interviews with study participants (Flick, *et al.* 2004, Glaser and Strauss 1967). Qualitative methods also allow for selected issues to be studied in depth and detail (Patton, 1990; Denzin and Lincoln, 2008) which often involves going into the 'field', or into the 'real world' to get close as possible to

capture what is actually happening (Patton, 2002:48). The researcher can then observe people in their natural setting and study how this shapes their interpretation of the phenomena under study (Denzin and Lincoln, 2000).

Although a much smaller number of people are often recruited than when quantitative methods are used, the purpose is to gain a deeper understanding of the situation and experience of those involved. The researcher becomes the instrument within the study design and methods, to capture the experience of a situation and is guided by the research objectives (Creswell, 2009; Miles and Huberman, 1994). Although this last statement could also be true of quantitative methods, the defining characteristics of qualitative research includes the importance of participants, the flexible nature of the research design (Lewis, 2003) and the unique approaches to data management and analysis (Miles and Huberman, 1994; Patton, 2002; Denzin and Lincoln, 2000). According to Denzin and Lincoln (2008:31) 'all qualitative researchers are guided by highly abstract principles'. These principles combine a belief on the nature of reality (ontology), what is known about the relationship between the inquirer and the known (epistemology) and how do we gain knowledge about the world (methodology) (Denzin and Lincoln, 2008). Lewis (2003) argues that a good qualitative study design is one that has a clearly defined purpose and that there is a clear rationale for the choice of research objectives and methods which will generate valid and reliable data.

3.3.1 Theoretical Framework

Qualitative research is often concerned with how individuals construct and make sense of the world (Robson, 2011). Qualitative methods allow selected issues to be studied in depth and detail (Patton, 1990). Although often a much smaller number of

people are included in the samples than in quantitative methods, the purpose is to gain a deeper understanding of the situation being investigated.

Qualitative researchers can utilise different approaches and methods such as ethnomenthology, phenomenology, hermeneutics and naturalistic inquiry (Denzin and Lincoln, 2008). Robson (2011:24) suggests that social constructionism is highlighted as a 'broad based mainstream qualitative approach with affinities to phenomenology and hermeneutic approaches.' Social science theory which includes; communication, psychology, sociology and anthropology, can also help to guide qualitative research and help to explain, predict and understand the phenomena under study. When consideration was given to the design of this research the intention was to explore the experience of family caregivers but not have preconceived ideas about the outcome of the research or how the participant's reality was, and is, constructed in relation to dementia and end of life care. This study was not intended to be an in-depth psychological profile of the family caregivers, nor was it intended to give a sociological understanding of the family caregivers decisions. It was also not intended to be an anthropological study to discover new beliefs and customs. Communication does play a vital part in ACP discussions and this is referred to in the discussion chapter. The intention of this study was to inform the future practice of health care professionals when undertaking ACP with family caregivers of people with dementia and give some insight into what does and what does not constitute effective practice in this emerging field. This information can be used to develop services and care and inform future lines of research inquiry. This study is therefore identified as a descriptive qualitative study based on the principles of naturalistic inquiry (Polit and Beck, 2010).

Naturalistic inquiry emphasises the human experience in the context of the participants' own social world. It therefore usually takes place in the field and so the findings from in-depth qualitative research are frequently caught up in the real life experience of people with first hand experiences of the phenomena (Polit and Beck, 2010) to potentially clarify the various dimensions of the subject under study. There are however limitations to naturalistic inquiry which the researcher should consider when designing qualitative research study. This includes the fallibility of human beings to represent accurately their experiences of the social world in which they live (Polit and Beck, 2010). Human beings are also sensitive to the experience and situation in which they find themselves and the complexity of how this has shaped their attitudes and behaviour (Cresswell, 2009).

In the absence of specific research or a well established theory it is difficult to justify a theoretical framework for this research study. Ideally a theoretical framework should connect the researcher to existing knowledge and the key variables which influence a phenomenon of interest (Polit and Beck, 2008). Greenwood and Levin (2008:70) accept 'that the world does not issue problems in neat disciplinary packages'. Polit and Beck (2008) suggest that not every study is based on a formal theory or conceptual model but rather a theoretical rationale or orientation. Qualitative inquiry is a field of inquiry in its own right according to Denzin and Lincoln (2008).

Previous research as identified in chapter two, suggests some of the key issues in ACP and its relevance to the end of life care needs for people with dementia, however

despite the support for ACP this is neither well established nor evaluated to inform practice. What is also not known is the experience of those family caregivers who are consulted to contribute to ACP.

Knowledge that is currently known includes; the family caregiver's burden that is experienced as a result of the dementia journey; that end of life care for people with dementia is sub-optimal; that there are certain factors which are likely to preclude participation of family caregivers in ACP; and care home staff often require additional education and skill development in meeting the palliative care needs of people with dementia. However it was difficult to identify the relationships among these variables and to set limits or boundaries for this study from the current research. Despite this emerging knowledge there is a lack of indicators and criteria that enable a sharp picture of how ACP is facilitated with family caregivers and what if anything will enable a satisfactory completion of an ACP.

Despite the absence of a distinct theoretical framework for this study, the conceptual framework / index as indicated in Figure 3.1 identified ideas which exist in the literature to enable a guide for this study as an initial starting point for the purpose of organising and thinking and providing direction.

This research study has sought to understand how ACP can be facilitated by using the experiences of family caregivers who have undertaken ACP to inform practice and services.

3.3.2 Populations and Settings

The specific nature of the research required the selection of a setting that, by virtue of the relationship to the study objectives, would enable the recruitment of suitable participants who were able to provide rich and relevant information (Lewis, 2003). The chosen care setting was a specialist dementia unit within an independent nursing home provider in a large urban town (population 43,155) within the City of Salford, Greater Manchester.

Salford is described as a close knit, inner city and manufacturing town and includes low income families living in estate-based social housing (20%) and older families living in suburbia (13%) (NHS Salford, 2010). Salford (population 218,000) is a city that is affected by inequality; high levels of deprivation, unemployment, crime, smoking, alcohol and drug abuse (NHS Salford, 2010). Notable features of the population distribution of Salford include an increasing elderly population, a significant proportion of the population recording disability (20%), a predominately white population with only 5.8% being made up of other ethnic groups and 66% of all mental health service costs are used for dementia which is far higher than for all other conditions put together (NHS Salford, 2010, Kings Fund, 2008).

The independent care setting chosen for this study provided nursing and personal care for up to 98 residents within the category of old age (aged 65 years plus). The setting employed approximately 120 care staff, 39 of whom were Registered Nurses (RN/RMN) the rest being mainly Health Care Assistants (HCAs). There were 13 GPs attached to the care setting. This purpose built care home was divided into five units. One of the five units accommodated 18 residents with dementia who were considered

to be in the advanced stage of the disease and was dependent on nursing care for their physical and mental health needs. This was the chosen setting for this study.

This specialist dementia unit reported that they had fully implemented the end of life care pathways: the GSF (DH, 2008) and the LCP (Ellershaw and Wilkinson, 2011) to facilitate palliative care for people with advanced dementia, which included ACP. Admission criteria for residents to this care setting included, confirmation that they were in the advanced stage of the disease and required a combination of both specialist mental health and generalist nursing care skills. Access to the care setting was negotiated with the Matron/Manager of the care setting and the senior nurse of the specialist dementia unit.

3.3.3 Sampling Strategy

The sample chosen for this study reflected 'purposeful sampling'; selecting participants that represented the topic under study in order to address the research objectives. Polit and Beck, (2010) suggest that purposeful sampling is a deliberate attempt to target specific characteristics of a chosen group to generate appropriate data, so was ideal for this type of study. The criterion used for the selection of study participants was used to represent and epitomise the features of relevance to the investigation (Richie, *et al.* 2003).

Silverman (2010) demands that we must think critically about the parameters of the population we are studying and so we must choose the sample very carefully and overcome a tendency to select participants who are likely to support the argument or research objectives. To address the potential for bias, an open invitation was made to

all the family caregivers of people with advanced dementia within the specialist dementia unit; whoever responded was accepted unconditionally to participate in the research. As Bernard and Ryan (2010) suggest, often researchers have to take what they can get, particularly when the population under study is considered to be special or hard to find. Access and implementation of palliative care in all care settings for people with advanced dementia, as discussed in chapter two, is still in its early stages within the United Kingdom and so the opportunity and convenience of this care setting was suitable to meet the study objectives.

The sample size selected for interviews are usually small, in part due to the time consuming nature of undertaking qualitative interviews and the large amounts of data generated. Travers (2001) suggests there is no fixed rule on how many interviews are needed, however it is essential to obtain sufficient data to explore and identify emerging themes, issues and topics from a small number, to be representative of the experience of the intervention (Bowling, 2009). It was anticipated that due to the small numbers likely to respond, all participants would be interviewed. The recruitment of family caregivers ceased when it was acknowledged that the data had reached saturation point and no further recruitment was initiated which included those who had not yet responded. Data saturation is interpreted as the point at which the arguments and descriptions presented by the study participants become redundant as no new information is obtained and a sense of closure is attained (Polit and Beck, 2010).

3.3.4 Criteria for Selection

Rubin and Rubin (1995) cite three guidelines for selecting study participants when designing a purposive sampling strategy; they should be knowledgeable about the situation; they must be willing to talk to the researcher; and they should be representative of a range of points of view. To facilitate the appropriate selection of study participants, discussions took place with the Matron and the Senior Nurse from the specialist dementia unit about the implementation of the ACP. Care planning notes for each resident confirmed the completion of an ACP with the identified next of kin, which usually involved the family caregiver responsible for decision making and with the appropriate power of attorney. It was important to identify with the Matron and senior nurse whether any potential participants should be excluded for reasons of compassion, for example those family caregivers who were currently experiencing a relative within the unit who was considered to be 'dying'. Interviewing participants who were recently bereaved (within days), or those whose relatives were currently on a LCP suggesting death was imminent, were initially considered but not automatically excluded.

As a result of this initial discussion, all family caregivers involved in the care of their relative with advanced dementia, who resided in the specialist dementia unit, were invited to participate in the research study in an attempt to obtain a sample that was as diverse as possible within the boundaries of this one setting and the defined population (Richie, *et al.* 2003). The family caregivers had had previous experience of caring for the person with dementia, either living with the person as a spouse, or supporting the person within the community for example a granddaughter, daughter, son, brother and niece. All participants were identified as being proxy decision

makers, which were identified as the 'next of kin' by the nursing home manager and senior nurse and were reported to be instrumental in acting on behalf of their relative with dementia. This included facilitating their place within long term care, managing their financial arrangements and being involved in ACP relating to end of life care with the care home manager and senior nursing staff (see figure 3.1). No care setting residents had an external advocate appointed.

Each identified family caregiver was written to and advised of the purpose of the study and informed how their experience would be valuable to the research in understanding the needs of people with advanced dementia who are at the end of life (Appendix 4). A contact slip was included with a stamped addressed envelope and the researcher's contact details (telephone and email address) (Appendix 5). Only once a contact slip had been returned would contact be made. Interviews were only initiated once the family member had responded as a result of one of the suggested communication methods. Participants were then given the opportunity to discuss the study and their potential participation and choose the location of the interview and the method, for example, telephone or face to face interview.

An opportunity to discuss the research with the Matron of the care setting was also suggested to the potential participants, thus confirming the credibility of the research. The sample inclusion criteria meant that study participants at different stages could be explored, for example, relatives who had recently suffered bereavement, those whose relatives were currently on a LCP and where death was imminent, and those whose relatives were in the advanced stage of the disease but not considered dying or near death.

Figure 3.1. Plan for Selection of the 'Cases'.

Fieldwork preparation and participation, the choice of data collection methods and how participants could be encouraged to engage with the study were all considerations. Research suggests that recruiting participants for interview on sensitive life events, including those recently bereaved, can be challenging and therefore samples are often small (Dyregov, 2004; McPherson and Addington-Hall, 2004; Addington-Hall, 2000; Sque, 2000; Parkes, 1995). This can be for a variety of reasons which includes the potential distress and the vulnerability of the research participants, some of whom will be bereaved (Addington-Hall, 2002). Addington-

Hall (2002:223) states that 'the frailty of palliative care patients presents challenges in deciding on appropriate data collection methods and tools'. Parkes (1995) who developed guidelines for conducting ethical bereavement research suggested that researchers should have knowledge of the bereavement process to prevent harm and should locate sources of help and support if required. Ethical issues will be discussed in more detail later in this chapter.

3.3.5 Methods of Data Collection

Dementia has had a reputation of being an under researched area and there is a limited knowledge base concerning living or caring for people with dementia in comparison to other conditions such as cancer, as discussed in chapter two. The purpose of this study was to gain insight into the experience of making plans for a relative with advanced dementia when at the end of their life using ACP, and therefore qualitative interviewing was an appropriate choice of collecting data to address the study objectives. Interviews should provide insight from the family caregivers' perspective and provide opportunities to identify gaps in provision and also opportunities to enhance the understanding of ACP and its potential for use in nursing homes (Stewart, *et al.* 2011).

The data collection method chosen for this study was semi structured, in-depth interviewing and was undertaken during one episode of fieldwork, within one care setting. A guided interview with study participants was the chosen method of data collection (Appendix 6). Interviewing is currently a method by which social scientists engage with issues that concern them and this then enables a special insight into the lived experience (Atkinson and Silverman, 1997) of a specific issue or

phenomenon. Patton (1990, 2002) suggests that qualitative inquiry methods promote empathy and give the researcher an empirical basis for describing the perspective of others whilst also reporting his or her own perceptions and insights as part of the data. Empathy is therefore an approach towards the people the researcher encounters and should allow the participants freedom to express their experiences about the topic under study. Empathy, according to Patton (1990) develops from personal contact with the people being interviewed and involves being able to take and understand the position, feelings, experiences and world view of others. This view is shared by Seale, *et al.* (2004) and Rapley (2007) who suggest that interviews are social encounters and allow participants to collaborate or give versions of their past and future experiences, feelings and thoughts.

It is worth noting why inquiry by observation was not chosen for this study. Patton (2002) argues that direct observation may be the best approach to fully understand the complexity of a situation. Observation of the interactions between the care staff, family members and carers and the dying person with advanced dementia could potentially have yielded data to observe the social event of ACP, the dying process and the events prior, during and after the event of death (Polit and Beck, 2010; Patton 2002).

Lawton's (2000) observational study of dying patients within different care settings and the consequential social interactions with people associated with the dying person highlighted the value of viewing the dying in the context of their social world, regardless of the setting. Murray, *et al.* (2007) also used a variety of methods in two longitudinal studies designed for lung and heart disease in which transitions of

disease progression, including the terminal phase, were observed and examined from a variety of perspectives.

However within this research the focus was on the experience of ACP with the family caregiver and so the detachment of the researcher away from the dying person was important. This was to ensure the researcher remained objective and did not provide a 'mirror' based on what the researcher had observed in the care setting (Patton, 2002; Hennink, *et al.* 2011). It was essential that the experience was reported from the interpretation of the family caregiver. Being observed during the ACP interview could also make the family caregiver self conscious and anxious (Patton, 2002; Hennink, *et al.* 2011) and influence behaviour, decisions and discussions by both the staff conducting the ACP interview and the family caregiver involved (Oliver, 2010). Although it would have been useful to be able to listen and take field notes during the ACP interview the family caregiver would have had to get used to the researcher's presence and be able to feel at ease in order to be completely candid with the member of staff conducting the ACP interview (Hennink, *et al.* 2011). This may have influenced the situation and outcome of the ACP.

3.3.6 Semi Structured Interviews

Qualitative interviewing is not an easy option and requires intense listening and a respect and curiosity about what people say. It also requires a commitment to really hear and report what people tell you and share during the interview (Rubin and Rubin, 1995; Hennink, *et al..* 2011). Using semi structured interviews each participant was asked a set of similar questions to ensure specific topic areas were covered. Focused interviews were developed in the 1940s by Merton and Kendall (Merton, *et al.* 1956;

Merton and Kendall, 1945) and focus on a subject or topic of conversation determined in advanced, in an attempt to collect reactions and interpretations (Hopf, 2004). In this study, semi structured interviews were chosen to seek out explanations of what happened during the ACP process, and for this reason the interviewer needed to keep the conversation on specific topics and pursue them until a satisfactory answer was obtained (Rubin and Rubin, 1995). The interviews, as in this study, were conducted with a relatively open format, not only to address the specific topic areas but also to give interviewees an opportunity to raise issues that had not been anticipated (Hopf, 2004). Semi structured interviews also provided structure which enable possible comparisons across interviews because respondents were asked the same or similar questions. This also had the advantage of being flexible so the interviewer could modify the order and details of how topics were covered (Bernard and Ryan, 2010). This is appropriate for this study, as the sensitive nature of the questions and topic areas required flexibility, so as to enable each of the participants to answer the questions in their own time and at their own pace (Fontana and Frey, 2008). When dealing with very emotive topics the researcher also needed to be sensitive on how and when to introduce questions and prompts. Therefore when planning the design of focused interviews, Merton, *et al.* (1956) developed the following quality criteria for deliberation when designing and conducting interviews; *Scope, Specificity, Depth and Personal Contact.*

Scope: the spectrum of the problem should not be too narrow (Merton, *et al.* 1956) and participants should have maximum opportunity to react to the situation. When designing the interview strategy, researchers have three strategies to choose from; the informal conversational interview, the general interview and the standardised open-

ended interview (Patton, 2002). The interview questions and probes in this study were sufficiently comprehensive to enable the participants to give details of their experience, but also allowed for additional information which they may feel was relevant (Hennink, *et al.* 2011).

Specificity: the topics and questions that occur in the interviews should be dealt with in a specified way (Merton, *et al.* 1956). This allows the participants to focus on specific memories and feelings. In this study the order of questions allowed the 'journey' of dementia to be described from their diagnosis, admission to the care setting and the discussion relating to end of life. Patton (1990) argues that neutrality can facilitate rapport and help build a relationship that supports empathy through the non-judgemental approach by the researcher. Study participants should feel supported in their discussions but also feel comfortable to contribute honestly during data collection. Objectivity of the researcher was essential if the researcher is called upon to render judgements about the programme under study.

Depth: interviewees should be supported in presenting the affective, cognitive and value related meaning which particular situations have for them (Merton, *et al.* 1956). There was a need for sensitivity in this study when asking questions that may evoke an emotional response and so ethical values continued to influence the research activity. It was necessary to prepare in advance for participants' emotional responses so that questions could still be asked to ensure depth of the interview, but also that appropriate responses from the researcher could be initiated. This included preparation prior to the interview to brief participants on the content and focus of the interview, pausing when appropriate, seeking consent from participants to continue

and opportunities to debrief following any distress. These issues will be discussed in more depth later in this chapter.

Personal contact: the personal context in which the analysed meanings and reactions are located must be adequately recorded (Merton, *et al.* 1956). Demonstrating interest in the interviewee should encourage openness and honesty. The standardised interview, as used in this study, consisted of a set of questions carefully worded and arranged with the intention of guiding each study participant through the same questions using almost the same words.

Field notes supported the tape recording to emphasise non verbal, emotional responses from participants. Interviews aim to obtain true meaning that individuals assign to events and experiences (Bowling, 2009) and so field notes can support recorded transcripts if the researcher feels that body language may have indicated certain emotional responses. The information obtained during an interview is dependent upon the interviewer (Patton, 2002). Bowling (2009) suggests the researcher must ensure the study participants are the subjects of the interview and not the objects, which Bowling (2009) also suggests places emphasis on the experience and subjectivity as the route to theory.

3.3.7 The Interview Schedule

An interview schedule was then designed to meet the study objectives. The interview schedule designed for this study used the GSF for end of life care (DH, 2008) and therefore dealt with delicate and complex issues of death and dying in the context of ACP (Appendix 6). Interviews provided an opportunity to focus on the individual

study participant's experience (Lewis, 2003; Patton, 2002; Denzin and Lincoln, 2008). This also provided an opportunity to conduct an investigation of the understanding of the individual within the context of their own setting. The use of open ended questions, carefully worded and arranged, was used with the intention of taking each study participant through the same order and asking them the same questions (Patton, 2002). This increases the opportunity to compare responses and to facilitate organisation and analysis of the data (Patton, 2002). The design of the interview schedule used in this study was scrutinised to ensure the interviewer did not lead or present confusing statements to the participants; that the participants were given the opportunity to refuse or withdraw information with which they were uncomfortable and that they could omit to answer anything they did not feel they could answer with any authority. The intention was to attempt to gain insight into the interventions relating to the goals of GSF and ACP and see if they were living up to the expectations of those involved in their application, as detailed through the experience of family caregivers. Also, retrospective questioning meant that earlier stages could be explored. For example, how these related to the personal circumstances of individual study participants, to examine their role and expectations of how the participants experienced the 'journey' of the person with advanced dementia and how they were designated as proxy decision makers.

The main themes within the interview schedule were as follows:

- Descriptions of the disease trajectory of the participants' relative with advanced dementia, the past history, care arrangements, admission to care home setting.

- Description of the experience of the ACP process with care setting staff.

- The experience of the days prior to the event of death (if applicable).

- The knowledge and understanding of the GSF in relation to end of life care.

Interviews were conducted individually and were focused, following the pre-prepared set of questions/prompts derived from the research study objectives (Appendix 6). Questions or prompts were specific, situational and contextual to the study objectives and encouraged an interactional exchange. They were sequenced in a meaningful way that 'encouraged cooperation and candour' between researcher and study participants (Polit and Beck, 2010:345). However it was also important to maintain a neutral objectivity. On the one hand participants needed to feel comfortable about discussing the ACP openly and honestly without fear of 'saying the wrong thing'. This was achieved through interviewing the study participants within their own natural environment (home), at a mutually convenient time and in a place sufficiently quiet in which they were unlikely to be disturbed. It was important that participants were assured of confidentiality, were comfortable with the device being present and that consent was sought prior to commencement of the interview (Yin, 2009).

Hermanns (2004) describes the interview as a drama which requires social skills of its participants and not merely the interviewer's ability to ask clever questions. As discussed in chapter two, advanced dementia is a complex syndrome which is complicated by the lengthy disease trajectory from diagnosis to death. It is considered to be a distressing condition for both the sufferer and the family members who witness the cognitive and physical decline of the individual. Hermanns' (2004)

description of a 'drama' fits well with this research and this was therefore explored to describe the interview process with the sample population, this included the briefing, the creation of a good atmosphere, giving the interviewee opportunity to open up and giving the drama an opportunity to develop to maximise data collection (Hermanns, 2004).

3.3.7.1 The Briefing

There is a need to make clear the purpose of the interview, how it will be done and where it will take place, in order to create a natural involvement and encourage conversational competence (Rubin and Rubin, 1995; Hermanns, 2004). At the start of all interviews it was important to confirm the purpose of the interview, obtain informed consent, seek permission for audio recording and confirm the reporting arrangements of the final study (Hennink, *et al.* 2011) (Appendix 7).

The family caregivers when contacted were given an opportunity to ask more questions or clarify any aspect of the research prior to taking part. They were also reminded of the research and its purpose before the interview took place. This was facilitated through the use of an information sheet and a consent form. Respondents were given the opportunity to decide when and where they would like the interview to take place so as to minimise the disruption to their everyday lives. It was important to establish early during the interview process a sense of trust and that their experience or story was worthy of being told and was worthy of being documented. This was achieved by confirming the importance of their contribution to the research, the use to which their contribution would be put and the acknowledgement that their relative's story was worthy of being heard. This may give some comfort to the

acknowledgment of the emotional journey that the person with advanced dementia has travelled and give the family member an opportunity to talk about the person as they once were.

3.3.7.2 Create a Good Atmosphere

Opening questions were chosen carefully to build a rapport with the interviewee so they felt as comfortable as possible before the key questions were introduced (Hennink, *et al.* 2011, Fontana and Frey, 2008). This also included being receptive to what the interviewee was communicating, other that the information they provided. Showing understanding and getting the facts and basic descriptions (Rubin and Rubin, 1995; Hermanns, 2004) are important and even though they may initially be broad questions, they are still related to the research topic (Hennink, *et al.* 2011). For example interviewees were asked to give brief biographical information relating to their relatives prior to the diagnosis of dementia.

Key questions involving sensitive subjects such as ACP relating to end of life care can create stress in some family caregivers, who react to their recollections of the events they have been involved with, both past and present. It was important that throughout the interview process the family member was given an opportunity to relate the facts as meaningful to their own experience and understanding. Rapport was important with the study participants so they would feel safe to answer questions and allowed the collection of detailed information to understand the issues from their own perspectives (Hennink, *et al.* 2011).

3.3.7.3 Give the Interviewee Opportunity to Open Up

The interview is a social interaction, different than normal conversations (Robson, 2002), which is more a collaborative effort to provide a negotiated meaning to a social situation (Fontana and Frey, 2008). Hennink, *et al.* (2011) suggest that it is important how the interviewer presents themselves and how the researcher's characteristics can influence the information gathered and ultimately, the quality of data collected. Social skills and flexibility require the interviewer to multi-task during the interview, observing the environment, motivating the interviewee, and showing empathy and respect for the lifestyle and beliefs of the interviewee (Hennink, *et al.* 2011; Robson, 2002). Issues such as interviewer choice of clothing, the use of equipment, the presence of an identification badge, the seating arrangements and the personal space during the interview were all important considerations (Fontana and Frey, 2008). However as well as putting the interviewees at their ease, it is also important to retain independent interest which allows them to display a range of personality traits and emotions without overprotecting and just getting facts and basic descriptions (Rubin and Rubin, 1995; Hermanns, 2004; Wengraf, 2001; Berg, 2010).

It was therefore essential to create a positive and supportive environment so the family caregivers felt safe to discuss what they believed relevant and where they also felt safe to demonstrate emotions. The family caregivers had an opportunity to demonstrate a range of feelings and experiences, associated with their experience which included embarrassment, anger, frustration, despair, humour, distress and guilt. A reciprocal relationship was facilitated to develop as the interview progressed and family caregivers responded to positive body language and supportive

acknowledgement of their feelings throughout the interview (Robson, 2002). The

purpose was to encourage an open and honest discussion of end of life care decisions.

3.3.7.4 Maximising the Opportunity to Capture the Data

Robson (2002) suggests that interviewers should listen more than they speak, ask

short and easily intelligible questions that stimulate the interviewee, ask for concrete

facts from the interviewees 'real world' and use concrete terms that the interviewee

uses. Robson (2002) also suggests that it is important to enjoy the experience, or at

least look as though you do, especially through the facial expressions you may use.

The semi structured interview schedule guided the discussion and ensured the

relevant topics were covered. Asking difficult questions, toning down the emotional

level so the respondent feels good about helping you, and finally closing whilst

retaining contact for the future (Rubin and Rubin, 1995; Hermanns, 2004) were

considerations when designing the interview schedule. Appropriate questions and

probes were included in the design of the interview. Probing is the key to successful

in-depth interviewing (Bernard and Ryan, 2010) and a series of probes was used to

guide the conversation (Rubin and Rubin, 1995) (Appendix 6). Bernard and Ryan

(2010) describe various strategies to use when probing respondents during interviews,

such as the silent probe, the echo probe, the uh-huh probe, the tell me more probe, the

long question probe and baiting – the phased assertion probe. These strategies

suggest that the focused interview becomes a structured conversation in which the

researcher pursues answers until a satisfactory answer is achieved. Although this is a

guided conversation, it can also initiate spontaneous responses from participants to

the interview questions. It must also be understood that it was important to accept

how people understand 'their world' and how values and views differ from place to place and, in this respect, the need to demonstrate an empathetic understanding of the world the participants reflected upon (Rubin and Rubin, 1995; Hermanns, 2004). Fontana and Frey (2008) acknowledge the complex and difficult nature of interviewing people in their natural settings as you enter their social world and the interviewer should expect the unexpected.

It was important that the participants did not feel vulnerable, after discussing emotional and sensitive topics, which exposed them to revealing information about their close family member with advanced dementia. Interviews should not end abruptly and Hennink, *et al.* (2011) highlight that it would be unethical to leave an interviewee in an emotionally vulnerable state or with painful memories. Closing questions become much broader towards the end of the interview (Hennink, *et al.* 2011). During the interview the interviewer and interviewee have become connected (Hennink *et al.* 2011) and the interviewer needs to reduce the rapport and create a distance. It was also essential to help the interviewee to calm down and feel protected as the interview came to an end. Rubin and Rubin (1995) suggest that asking respondents to narrate their victories or positive experiences is essential to help them gain control and feel protected. Respondents were also given the opportunity to state any additional information that they felt was relevant at the close of the interview and this allowed them to feel good that their contribution was valued. This confirmed the relevance of their experience to help others in a similar or future situation.

3.4 Ethical Considerations

When discussing care at the end of life, some participants involved in this study became emotionally distressed. Research ethics are concerned with the collection and dissemination of trustworthy information which should cause no harm to participants engaged in the study (Rubin and Rubin, 1995). Fontana and Frey (2008) question the ethicality of the interview if the interviewer uses techniques and tactics to manipulate the respondents rather than treat them as individual humans. The researcher may have an interest in the success of the research either through publications or notoriety. Collecting high quality information is dependent on the co-operation of the conversational partner (or interviewee). Encouraging people to talk openly and honestly about their experiences can incur serious ethical obligations and according to Rubin and Rubin (1995) this includes avoiding deception, seeking permission to record, being honest about the intended research, ensuring interviewees are not hurt, emotionally or financially, and the opportunity to retract any information given (Rubin and Rubin, 1995). Any research undertaken should therefore give due consideration to the ethical and moral implications, particularly when engaging in sensitive issues such as end of life care.

The Research Governance Framework for Health and Social Care (2005) was consulted in preparation for the ethical approval required for this study (DH, 2005). Guidance and application for ethical approval for health and social care is through the National Research Ethics Service (NPSA/NRES, 2010) formerly the Central Office for Research Ethics Committee (COREC, 2006). Liverpool John Moores University guidance for ethical approval was also considered prior to commencement of any data collection. Universities operate a separate system to the NHS and for this evaluation advice from both committees was sought. Liverpool John Moores University

(LJMU) provides a code of good practice to academic staff and research teams which closely follows the statement on Safeguarding Good Scientific Practice issued by the joint Research Councils in 1998 (LJMU, 2008, 2007)

The study was considered by the then COREC as a service evaluation and therefore did not require ethical approval by a NHS Research Ethics Committee or approval from the NHS R&D office (Appendix 2). LJMU ethics approval was still required and application procedures including consideration of NHS Governance were followed. The application for ethics approval was submitted to the next available University Research Ethics Committee, University Ethics approval was granted for a period of 5 years (Appendix 3).

Despite this research not requiring NHS approval, it is acknowledged that if this application was to be repeated today this may now be a requirement following a revision of ethical guidelines (NPSA/NRES, 2010; DH, 2005).

Hennink, et al. (2011) makes the point that ethical issues do not stop just because the researcher has been granted approval. The areas addressed before, during, and after the research was initiated included informed consent, confidentiality, data protection, right to withdraw, potential benefits and the minimisation of harm (Royal College of Nursing (RCN), 2009). The nature of the subject matter indicates the possibility of potential distress from discussing accounts of death and dying in others, some of whom were close family members and/or care staff who had an emotional attachment to the resident. The need to balance risks and benefits to participants was an important consideration (Johnson, 2007), for example, who will benefit directly or indirectly (Hennink, et al. 2011)? Research participants were fully informed about the purpose, methods and intended possible use of the research through the information sheet and

introductory letter sent as an invitation to participate in this research, so that an

informed choice could be made (Johnson, 2007) (Appendices, 4 and 7). Care was

taken in this research to support the interviewees, particularly the family caregivers to

avoid any undue distress when reporting their experiences on behalf of the person

with dementia.

McHaffie (2000) reports that the research world operates on the basis of trust and that

any limitations, delays, unexpected hitches or ambiguous questions are acknowledged

rather than pretend the exercise was perfectly planned and executed. The need for

honesty and trustworthiness in the data are essential.

Research participants participated in a voluntary capacity and were free to withdraw

at any time. Consent was freely given as participants, once agreeing to the interview,

were then reminded of the method and intended purpose of the research prior to

signing the consent form. The production of the participant information sheet and

consent form was guided by the university policy documents (Appendix 7) (LJMU,

2007, 2008). Participants were also given the opportunity to view a copy of their

written transcript. Only family caregivers who wished to be involved were

interviewed. Participants were able to choose the location of their interview to

minimise any disruption to their usual routine and they were also informed that they

could withdraw at any time and were under no compulsion to take part.

Interviews with family caregivers involved the divulgence of personal information on

behalf of the resident with dementia. The interviews with family caregivers focused

on the support offered and quality of information given to the family caregivers

regarding end of life care options and to what extent they were involved regarding the

care and treatment options for their relatives. The data were collected using a digital tape recorder and participants were informed of how this information would be safeguarded. The confidentiality of this information supplied by the research subjects and the anonymity of the interview participants were respected (RCN, 2009). Interview recordings and transcripts were stored on a computer which was password protected and only available to the researcher. The interview transcripts were anonymised as much as possible by removing any information that may make the subject participants identifiable. Data for this research were treated as highly confidential, only the researcher had access to the audio tapes, transcripts and data (NMC, 2008). Data stored on the computer was anonymised through the use of identification numbers. No resident/patients documents were removed from the care settings.

As the interview schedule contained sensitive questions relative to end of life care and was likely to cause a degree of discomfort for participants, it was essential to plan for the likelihood of discomfort and distress, and in anticipation of this, to identify provision for the help that could potentially be solicited if required (Parkes, 1995; Jamieson and Victor, 2002). This was identified particularly for family caregivers of persons with advanced dementia and for those who had been recently bereaved. It was essential that when planning the research, due consideration and sensitivity was given to needs of the family caregivers and opportunities to debrief post interview were provided to ask questions and air any concerns. Sensitive topics may uncover painful experiences and as the researcher leaves the interview, the study participant may be left with feelings and thoughts promoted by the researcher's questions. It was important that the researcher allowed some time for a 'debrief' so that any anxieties

could be discussed. The researcher avoided the role of counsellor and was aware of the potential confusion that may present if the study participant became too distressed. It was essential that the researcher was alert for signs of distress and checked to see if the participant was willing to continue or offer to stop (Lewis, 2003). Participants were sent a thank you letter following the interview with follow up contact details, should they be required (Appendix 8). The letter was sent three days after each interview to give the participant time to reflect on the event and provide an opportunity to change their mind and withdraw (Sque, 2000).

A further essential consideration was the potential for possible disclosure of information from the interviewees that may indicate that they or their relative was at risk of harm. As a registered nurse and guided by the Nursing and Midwifery Code of Conduct (NMC, 2008) it is a requirement to disclose potential harm to vulnerable people. However it would also be appropriate to encourage participants to report it themselves or seek help and support and/or the researcher may need to report it on their behalf or support them in seeking help. It was therefore necessary, in anticipation, that any potential advice and/or information was selected from appropriate sources to meet the specific needs of study participants.

3.5 Data Management and Analysis

Qualitative data collection can be problematic as interviewees may present with poor recall, poor or inaccurate articulation and bias against, or for, a particular issue (Yin, 2009). Data collection must demonstrate rigour, representation and reflection of the data, which is able to withstand scrutiny and critical analysis (Polit and Beck, 2010). To assist with this, the interview schedule was subject to peer review prior to meeting

with participants. Interviews were recorded using a tape recorder; all interviews were transcribed verbatim and peer debriefing by the supervisory team was used throughout the data analysis to reduce the potential for bias.

Content analysis and thematic analysis are closely related and share many of the same principles and procedures (Joffe and Yardley, 2004). Thematic analysis attempts to extend what has been previously reported in previous research and to compare and contrast similarities across cases (Polit and Beck, 2008). Theoretically derived themes, according to Joffe and Yardley (2004), allow the researcher to replicate, extend or refute prior discoveries. Elo and Kyngas (2007:108) suggest content analysis as a research method for analysing data which can provide 'knowledge, new insights, a representation of facts and a practical guide'.

The paucity of research in how family caregivers experience ACP for people with advanced dementia indicated there is not enough former knowledge available. Content analysis assumes there are no preconceived ideas or assumptions but that the data is 'heard' and examined for explicit and covert meanings (Bernard and Ryan, 2010). Content analysis involves establishing categories and then either 'counting' the number of instances in which they are used or describing them qualitatively (Joffe and Yardley, 2004). Content analysis can be inductive, describing what is found in the data, making valid inferences which should be made objectively and systematically (Joffe and Yardley, 2004). Therefore content analysis has been chosen for this study in an attempt to increase understanding of the experiences of ACP and generate knowledge (Cavanagh, 1997).

Content analysis is a search for patterns within the data (Bernard and Ryan, 2010) and although this begins before the data collection, from the design of the interview questions, the patterns discovered within the interviews, should help to explain why those patterns were there in the first place. Miles and Huberman (1994) describe a classical set of analytical moves which have been used to analyse the data from this study. Content analysis includes; initial coding, identifying categories and sub-categories discerned from the data and linking the generalisations to a formalised body of knowledge in the form of constructs and theories (Silverman, 2010, Miles and Huberman 1994). Sub-categories with similar events and incidents are grouped together and form the main categories (Elo and Kyngas, 2007)

Interviews with family caregivers provided data on the experience of the implementation of the ACP process which is part of the end of life care pathway. The participants' transcripts were initially analysed individually, followed by comparing and contrasting the data for the final reporting. This involved breaking down the data into smaller chunks according to the content they represented (Polit and Beck, 2010). There was a challenge of reducing data for reporting purposes as this involved ensuring that the richness of the data is not lost and that there was consistency in translation (Polit and Beck, 2010). The transcripts in this study were read, re-read, organised, integrated and interpreted (Polit and Beck, 2008, 2010) into meaningful categories and sub-categories (Silverman, 2010). An index was devised from the interview schedule and the study objectives and this allowed for the identification and application of the codes to the transcript (Box 3.1). Once an index was generated this was then applied to the data sets (transcripts) and coding was undertaken using Nvivo v.9.0. Nvivo v 9.0 is an example of Computer Assisted Analysis of Qualitative Data

(CAQDAS) and was used to assist in the analysis of the interview transcripts. The coding assisted in the handling of large amounts of data to enable organisation of the data into manageable chunks (Silverman, 2010). In order to sort and organise the data, a more detailed examination followed where the coding process was applied following re-reading of each interview transcript.

Coding is considered to be an interpretive act (Silverman, 2010; Saldana, 2009) and is most often a word or short phrase that assigns a meaning for a portion of language from the interview transcript. Using the index (Box 3.1) as the guide, coding of each transcript was completed. Once the coding had been achieved it was then possible to undertake a higher level of abstraction and assign the sub-categories into categories by which to sort, encapsulate and present the data (Richie, *et al.* 2003). This allowed for the identification of the main categories and sub-categories for the purpose of analysis (Silverman, 2010).

Sub-categories emerge from the data and bring meaning and identity to an experience (Polit and Beck, 2008; Silverman, 2010). Although the research participants were asked the same questions it was not assumed that they would respond in similar ways. The sub-categories were identified from the data but also examined how they were patterned. This included timelines to highlight experiences or the sequences of events that influenced decision making and/or any factors, similar or individual, which challenged those decisions. Sub-categories were also examined to see if they only applied to certain people or in certain circumstances (Polit and Beck, 2008, 2010; Silverman, 2010) or at certain times. Once sub-categories and categories were identified, concepts and ideas emerged from the data and this included which were

discussed and how concepts were understood by each participant. However, it was also essential to not lose the integrity of the full transcript, note the location of an original piece of data and provide opportunities to assign data to multiple locations. The credibility and trustworthiness of these identified categories and sub-categories was assured by discussion and agreement with the supervisory team and their reading of a selection of the interview transcripts. There was then a search of the data to identify patterns of text which connect between the different transcripts.

Segments of each interview transcript were analysed for their consistency of emerging categories and sub-categories and also for the coherence of the sub-categories to identify any contradictions or the reporting of a different versions of event by any of the study participants (Silverman, 2010). The purpose was to demonstrate that core concepts were consistent in each interview transcript within the care setting. Any inconsistencies were identified and examined, not to eliminate them, but to understand why they occurred.

Quotes from the participants were selected to provide detail and evidence from the interview transcripts. Accuracy in reporting was essential to provide an honest interpretation of the participants' experience. To ensure the research will be understood and interpreted by others it is essential to have clarity of the results, so that even those not familiar with the subject could have an appreciation of the purpose of the research and the experience of the participants' voices (Rubin and Rubin, 1995). Silverman (2010) advises against the tendency of some researchers to select cases or results which are likely to support the argument. This has been avoided

through the exploration of the data and the identification of individual differences and

respect for each participant's unique experience.

Box 3.1 Conceptual Framework / Index

Conceptual Framework / Index for a study to explore the experience of ACP

amongst family caregivers and relatives of people with advanced dementia.

1. **Relationship to resident in care home**

2. **History**

2.1 Reasons for entering care home

2.2 Advice/information on long term care environments

2.3 Disease progression

2.4 Sources of support

3. **Advance Care Planning**

3.1 Experience of ACP

3.2 Discussions of care and treatment at the end of life

3.3 Views on hospitalisation

3.4 Flexibility of the document

3.5 Views on ACP

3.6 Role of the GP

4. **Care of the Dying Resident**

4.1 Place of death

4.2 Use of care pathway (LCP)

4.3 Views on quality of care given

4.4 After care including bereavement care

5. **View on GSF**

5.1 Relevance to dementia

5.2 Care arrangements in care homes

5.3 Other views on end of life care

5.4 Staff training/knowledge

3.5.1 Credibility and Trustworthiness

Patton (2002) states that the credibility of qualitative inquiry will depend upon three distinct elements; rigorous methods, the credibility of the researcher, and the philosophical belief in the value of the qualitative inquiry. Credibility refers to the extent that there is confidence in the truth of the data and the interpretation of them (Polit and Beck, 2010). It is therefore important to conduct a study that enhances the credibility of the findings. The sampling strategy selected and the recruitment from a specialist dementia unit adds to the reliability of this study. The specialist dementia unit removed some of the potential variables of a generalist nursing home which included issues relating to; admission criteria, undiagnosed dementia as a secondary condition, palliative care philosophy in the care homes, and the disease trajectory of other long term conditions.

A consistent approach to data collection was made to each participant or case who engaged in this study. This research involved the accurate reporting of participants' 'voices' in an attempt to gain an understanding of the experience of family members of people with advanced dementia. It was important that the outcome of the interviews was not prejudged and that any previous experience or 'insights' of the researcher was not detrimental, or did not influence the results (Gerrish and Lacey, 2006). Patton (2002:553) suggested that 'mental cleansing' should include consideration and engagement in the finding of 'alternatives, divergent patterns, and rival explanations'. Identifying and analysing any deviant cases was an important feature for the credibility and trustworthiness of the data (Silverman, 2006). Deviant case or negative case analysis provided an opportunity to find rival interpretations of the data (Patton, 2002).

Details of the research design and methods of data collection should be sufficiently transparent to any external reader so as to replicate the research if required. Robson (2011:486) suggests there are several 'tactics' that might be used to assess the trustworthiness of qualitative data analysis which includes the importance of checking and rechecking the data for accuracy, accepting the potential limitations of the data when drawing inferences from a non representative sample and acknowledging the potential for bias from the researcher and to the researcher following involvement in the study. Coding consistency across the interviews was important and was also subject to peer review to enhance the credibility of the results (Cresswell, 2009, Lincoln and Guba, 2000). This challenging academic exercise allowed for alternative explanations to be discussed and explained and to find strong supporting evidence to increase confidence in the findings (Patton, 2002). The codes were applied to the accurate transcription of the interviews and were then confirmed by the peer review of the supervision team.

The interpretation of the findings should be an accurate representation of the participant's responses (Polit and Beck, 2010; Cresswell, 2009; Lincoln and Guba, 2000). As in this study, the verbatim transcribing of the interviews, the accuracy of the reporting, the selection of appropriate text or quotes to confirm findings and the importance of peer review (inter coder agreement) all add to the trustworthiness of the findings (Cresswell, 2009). The experience that is being described by the research should enable the reader to develop a heightened sensitivity to the issues being discussed. Good analysis depended on integrity to make most sense from the data and required insight and objectivity. This research accurately portrays the information provided by the participants.

3.5.2 Transferability of Findings

Transferability refers to the generalisability of the data, the extent to which the findings can be transferred to, or can be applied to, other settings or groups. To be able to generalise the findings, suggests that the theory can be useful in making sense of similar situations and people. Patton (2002:582) suggests that 'when we give proper weight to local conditions, any generalisations is a working hypothesis, not a conclusion'. This research was conducted within the context of one specialist dementia unit; this was a small scale initiative and may not be transferable to other long term care settings. The knowledge gained from this can be useful in developing understanding and although not deemed 'scientific induction', it can provide a 'naturalistic generalisation' by recognising similarities as applied to other care settings (Patton, 2002:583). Generalist care setting staff can identify the experience of the family caregivers who are often solicited, in these settings, to make or contribute to the making of difficult decisions about end of life care for their relative, with or without dementia. The research should be sufficient in its reporting so that others can evaluate the extent to which the results are applicable to other contexts and settings (Polit and Beck, 2010). Experiences, expectations and interpretations of health and social care policy as applied to specialist areas of care such as dementia could have the potential to influence other long term conditions with lengthy disease trajectories.

3.6 Summary of Chapter Three

This research was designed to capture the experience of family caregivers of people with dementia who have been involved with ACP. The intention was to gain an understanding of the experiences of family caregivers who have supported a person

with dementia. The research site was a specialist dementia unit caring for people with advanced dementia, who were in need of physical and mental health nursing care and had implemented the ACP process. All relatives identified as the next of kin were contacted for potential recruitment into the study (purposeful sampling). Care and consideration was given to the potential distress if the resident within the dementia unit was in the last few days/hours of life and so the timing of the contact letters was given due regard following discussions with the Matron and senior nurse. Respondents were contacted following an initial response to the information letter. Interviews were arranged to suit to the respondent and data were then collected through the use of qualitative semi structured interviewing.

Appropriate strategies of data management and analysis demonstrated how this experience had impacted on their role in making proxy decisions which had the potential to impact on the person with dementia at the end of their lives. This was achieved through content analysis which involved a thorough examination of the data and the appropriate attachment of codes and the identification of categories and sub-categories. The intention was to seek commonalities and variations amongst the participants to explore the experience and factors effecting decision making without losing the integrity and richness of the heard data.

ACP, in relation to end of life care, is a sensitive issue and this exposed the study participants to potentially distressing memories and emotions. Ethical values were given appropriate consideration in the design of this study, to ensure that participants were treated honestly and respectfully and that distress was kept to a minimum. Parkes (1995) guidelines for conducting ethical bereavement research guided the

preparation of the interview schedule and the conduct of the researcher during the interviews.

Chapter five presents the findings from the data collection, management and analysis. Nvivo v 9.0 was used to assist in the coding and identification of the categories and sub-categories. Direct quotes from respondents are displayed to demonstrate the emerging topics within the data. Similarities and differences within the data is displayed and acknowledged and any deviant cases are identified.

Chapter 4:   Findings

4.1 Introduction

As outlined in chapter three, this research adopted a qualitative interviewing approach as the main method of data collection. Interviews with family caregivers provided data on the experience of the implementation of the ACP process which is part of the end of life care pathway (DH, 2007, 2008). Family caregivers were selected through purposeful sampling for inclusion into the study. The study participants were recruited from an 18 bed specialist dementia unit, situated within an independent sector care setting which had attempted to fully implement the end of life care pathways (DH, 2008) to facilitate palliative care for people with dementia. Admission criteria for residents were that they were in the advanced stage of the disease and required a combination of specialist mental health and generalist nursing care skills.

4.1.1 Study Participants

Eighteen family caregivers were contacted who had been identified in the care plan as participating in an advance care plan meeting. Two of the unit beds were unoccupied at the time of this study as the resident had died within the last three months. These relatives were also included within the initial sample.

Responses were sporadic over several months and included, family members of residents who had died within the last three to six months, residents with whom an ACP had been undertaken with the relative and those whose relative was considered to be at the end of life (last few weeks of life).

Twelve family caregivers responded to the request to participate in the research and be interviewed. Four family members did not respond. Two family caregivers responded but preferred not to be involved at this time, stating they were not ready to discuss the subject matter due to the recent death of their relative.

What follows is a summary of the study participants (Box 4.1); their relationship to the resident in the care setting; if an ACP was in place or had been discussed; if the resident's condition was 'at the end of life' and a care pathway had been initiated; and if the relative had died in the care setting with a pathway in place. The age range of the study participants was between 35 years and 82 years. Eleven participants confirmed that an ACP had been discussed. Six participants' relatives had died within the care setting within the previous three to six months. The identification numbers relate to the digital recorder code when downloaded onto a computer file.

Box 4.1 Characteristics of the sample population

Identification number: Digital recorder code	Relationship to resident	Age range	ACP currently in place for resident	LCP currently in progress (or prior to death)	Resident died with pathway in place
D003	Brother 1	76+	Yes	Not applicable	Not applicable
A0065	Daughter 1	46-55	Yes	Not applicable	Not applicable
D004	Daughter 2	46-55	Yes	Yes	Yes
C0053	Granddaughter 1	35-45	Yes	Not applicable	Not applicable
A0067	Niece 1	56-65	Yes	Yes	Not applicable
D001	Niece 2	46-55	Yes	Yes	Yes
B0061	Son 1	46-55	Yes	Yes	Yes
A0064	Son 2	46-55	Yes	Yes	Yes
B0052	Spouse 1 (Husband)	66-75	Yes	Not applicable	Not applicable
D002	Spouse 2 (Wife)	66-75	Yes	Yes	Yes
A0068	Spouse 3 (Wife)	76+	Yes	Yes	Yes
C0055	Spouse 4 (Wife)	76+	Discussed but not in progress	Not applicable	Not applicable

4.1.2 Data Management and Analysis

As stated in chapter four, the interviews were analysed using four main categories which represent the sections within the interview schedule (Appendix 6). The four categories were strongly related but are reported separately. Each main category is presented with sub-categories or classes (Box 4.2). For the purpose of reporting the findings, the family caregivers are referred to as the 'study participants' and their relative who has advanced dementia as the 'resident'. Direct quotes are used to provide the best exemplars from the categories and classes. Each quote is identified by the digital recorder identification code (for example D003) and the relationship to resident (Box 4.1).

One interview was identified as a deviant case and provided a differing interpretation from the respondent and added variability from the sample population. This is referred to later in the chapter as being 'deviant' (Section 4.6) and is reported as a separate 'case'.

Box 4.2 Main categories with sub-categories

Main Categories	Sub-categories
The Dementia Experience.	*Disease trajectory; diagnosis and support available; Admission to long term care*
Dialogue of Advance Care Planning.	*Experience of ACP; Relevance to people with dementia; Content of ACP; Power of Attorney; Euthanasia.*
Care at the End of Life	*Care pathways; Hospitalisation; Previous experiences; Staff training and education; Time to care; Role of GP.*
Future Priorities	*Suggested recommendations for improvements in care for people with dementia and their carer.*

4.2 The Dementia Experience

Participants were asked to provide information about their relative and their experiences of dementia. The responses provided an opportunity to identify the experiences prior to diagnosis and the events which took place prior to admission to long term care. The 'real world' context of the dementia experience was an important feature to establish if this had any impact on future end of life care decisions.

The experience of the disease was shared by the sufferer and the family as they both experience the change in relationship between husband and wife, mother and son and

brother and sister as the person they once knew 'disappears'. Lindstom, *et al.* (2011a) also confirmed that this 'anticipatory grief' is experienced at different stages from diagnosis to death. This is demonstrated in the following quote from a resident's husband:

"Yes, you've got to talk about it don't bottle it up ever...all the way through this illness I've told all the family exactly what's happening and why and it's been lots of tears everywhere. Put it this way it's been seven years bereavement, I've asked for counselling and have never got it. I've asked several times for counselling and have never got it. It happens doesn't it, she is my wife you just have to get on with it don't you. I have been like this for a while and so I know I get upset." B0052 SPOUSE 1 HUSBAND

The first part of the interview schedule allowed the participant to reflect upon their 'dementia journey' with the resident and their knowledge and skill development from diagnosis to admission to long term care.

4.2.1 Insufficient Knowledge of the Disease Trajectory.

Study participants expressed concern about not knowing enough about the disease trajectory of dementia. They reported that a lack of understanding of how the disease would develop and how changes in the behaviour of their relative could have been anticipated and managed may have increased awareness and preparation. One son and granddaughter of different residents expressed their understanding as:

"Just need to know how to cope with people with dementia, with the loss of memory and stuff like that. It's like you say everybody is different, it affects people differently, the progression in each individual is different. Just floored

at what she did really, couldn't predict anything at all and that's difficult. Like a ball, going down down down down down, eventually that'll be it. But you've no idea how big the bounce is. " B0061 SON 1

"Grandma first started showing signs... thinking back it was a good 20 years ago...just forgetfulness and stuff. Slowly it got worse she became more forgetful and she wouldn't go out of the house and she would have night terrors and she would phone at 3 o'clock in the morning saying someone was in the loft and was going to rape her and for ten years it got progressively worse and worse and I lived nearest 'cause she only lived a mile up the road. I was the one that was always there at 3 o'clock in the morning calming her down......... (Takes a breath, sighs) and then....I didn't know how to cope. " C0053 GRANDDAUGHTER 1

Information was reported as not forthcoming from health care professionals, which added to the stress and anxiety of the study participants. A lack of understanding and knowledge about dementia and its trajectory was cited by study participants as they found it difficult to obtain information. Most participants identified in the following quotes informal sources of help and information.

"Initially I didn't know anything about dementia, but I did find out various information about it; I've spoken to a few of the people who have got relatives who have it. " A0064 SON 2

"I mean Help the Aged they do a wonderful job. The Alzheimer's society they have been a great help to me it's only recently I found out about them. " B0052 SPOUSE 1 HUSBAND

Study participants also had uncertain expectations about how the disease would progress and what to expect in the end stages. This added to the uncertainty of the disease trajectory as reported by the two sons in the following quotes:

"I'd say it's important to make sure people are aware what the condition means, if you haven't had friends or colleagues with it, I imagine that could be very daunting. It's one of those things that if you're well informed you're more able to deal with things aren't you?" A0064 SON 2

"Yes. Over the years she'd keel over but she recovered. We were never quite sure when she did have a turn, if it was for the worst or if she was back on her feet again. At one stage she was asleep for six months, I think she got an infection, next min she's out of it for 6 months. And she was just on fluids, that concentrated drink kept her going." B0062 SON 1

The uncertainty of the disease trajectory and lack of information clearly creates an additional burden to an already stressful situation for the study participants.

4.2.1.1 The Experience of Advanced Dementia

Participants reported being upset when the person no longer recognised them or mistook them for someone else. Occasionally, study participants reported that there were glimmers of the person (resident) they once were. This appeared to make visiting the care setting difficult and in some cases the relative avoided or postponed visiting the care setting. The following quotes express the emotional context of visiting their relative in the care setting:

"Yes just bring them all to the XXX standard. Sometimes there is a smell sometimes not. If I don't go I am not made feel guilty because I can't go but I

don't like to see her like that. I cope better when I don't see her too much. She thinks you're the hairdresser or the manicurist. She thought XXXX was coming to do her feet." C0053 GRANDDAUGHTER 1

"Every now and again you'll say something to them and they will give you direct eye contact and you feel the family member is connected to you. Like they know what it is you're saying, yes? And that gives you some sort of comfort, but then it breaks your heart and you think well what if she doesn't recognise me. And then when you don't get no response for so many years. You think they're not there or are they in complete hell?" A0065 DAUGHTER 1

One participant expressed a desire for his wife to have suffered with cancer, rather than dementia and became quite angry during the interview, demonstrating strong feeling about the disease and the hopelessness he felt. This is illustrated in the following quotation:

"Oh don't misunderstand me please if it was cancer I would be tons happier, I could talk to XXXXXX, I could hold her hand when she's in pain or anything like that. I CAN'T TALK TO HER (raised voice). She's either asleep or miles away reaching for something that's not there. She rarely smiles now. That's nothing to do with the care she gets at the home that's brilliant, she's just in her own little world." B0052 SPOUSE 1 HUSBAND

A lack of communication with their relative was reported as being problematic and at times frustrating for the participants. The experience of frustration was also reported on how the initial diagnosis was made.

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4.2.2 The Experience of How the Diagnosis Was Made.

Study participants expressed concern that the diagnosis took too long to be identified. All related stories of having experienced difficulties with accessing appropriate specialist and support services.

"You know there was an examination by a specialist here and we went for a scan there and we waited months to get the results of the scan then we went somewhere else and we were just going round and round in circles and in the end I lost my temper a little bit and that when we went to see XXXX at XXX Hospital and he was very gentle and that was when he told us (becomes emotional) and from there is has just sort of gone downhill." B0052 SPOUSE 1 HUSBAND

"I don't really know because none of us knew what was really going on at first. At first we thought she was attention seeking because she wanted more all the time because she thought she hadn't seen us for days Maybe her GP could have spotted it early enough. It is one of those behind closed doors kind of illnesses which is silly because it is nothing to be ashamed of it's just the brain closing down." C0053 GRANDDAUGHTER 1

Relationships with health professionals could be problematic and participants were often relieved and grateful when the diagnosis was made following months and years of uncertainty.

"Physically it was draining, because I was working full time, my husband had had a heart attack so home life was chaotic and if she fell I was there in an instant no matter what, you know my boss was brilliant at the time. When we finally got a diagnosis that it was Alzheimer's it was like 'phew' finally someone is listening to us, you know." C0053 GRANDDAUGHTER 1

"When we eventually had a diagnosis, the communication we had from the consultant, I think he summed it up fairly well at the time, he said in his opinion it would be a very steady decline of memory and across the board and mental skills, some things accelerate some things don't, generally that's what he felt in me mum's case. In fact he was spot on really." A0064 SON 2

Once a diagnosis was made, accessing appropriate help and support was often difficult and was one of the most recurrent accounts for most of the study participants, examples of which are given in the following quotes.

"Yes, and she was ill a year before and she wasn't eating much, so basically she was existing on cranberry juice and that was it. In the last three weeks she just went downhill, and that was the hardest part really. I think that's where people really need help really, that's where you need support." B0061 SON 1

"You have police fire and ambulance the essential services that the country couldn't do without and they talk to each other a lot. But in the National Health Service they don't. I mean some of them in social services, some of them are really nice people and do a darn good job but some are a total pain in the rear end. But if they talk to each other if they speak about what the real problem is." B0052 SPOUSE 1 HUSBAND

This account from a resident's granddaughter acknowledged the importance of the role that the individual health professional who has the appropriate skills and knowledge of dementia, can contribute to the family carer experience.

"I don't think there was any (help) really we were just left to it you know as a family you deal with it I think his name was XXXX a very nice young man... and she let him in because she liked him.. And he recognised what was going on... and he worked on finding somewhere for her to be looked after properly

because by this time I was physically and emotionally drained, it was making me ill. And this man recognised what was wrong with grandma, diagnosed her properly and it's aggressive Alzheimer. Once we got him, we became more knowledgeable and more empowered to deal and cope with things that were going on. He gave us the knowledge of what we needed to know... he told us what we were thinking was right plus a bit extra and then he fought for grandma to go into XXX, he chose XXX as the best place for her and the XXX unit and he fought for her and he fought quite hard for her and for that I will always be grateful to him because it is a smashing unit it really is. I can't speak too highly of him." C0053 GRANDDAUGHTER 1

The quotes included in this section were typical of the difficulties relating to a diagnosis of dementia amongst the study participants. They often expressed frustrations that the diagnosis of dementia was difficult. The attitude, skills and knowledge of professionals appeared to have an impact on the dementia experience for the participants. The difficulties associated with the disease of dementia eventually appeared to lead to a crisis event and long term care admission.

4.2.3 Admission to Long Term Care

There were similarities between participants' experiences prior to and following admission to long term care of their relatives. Admission to long term care was often following an acute illness or injury in which the resident needed hospitalisation. A crisis event often included a fall in which an injury was sustained that required hospital treatment. The need for long term care became an urgent issue and one that required the study participants to research local care providers. A lack of knowledge about long term care facilities, provision and costs all added to the continued anxieties for the study participants.

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"It got taken out of our hands when she went walk about one night and she fell and broke her hip, which was the worst thing that could have happened but also the best thing that could have happened, because it was taken out of our hands, decisions were made for us, it was very difficult to look after her" C0053 GRANDDAUGHTER 1

"The relative is my aunt, dad's sister. She used to live on her own and was beginning to show signs of dementia. Then she fell at home and broke a couple of bones so she had to go in hospital. She had a rough time in hospital due to staff neglect. I tried to resettle her back in her home but she had become institutionalised in the hospital and perceived that to be her home. Therefore she had to be readmitted until we could find an alternative to hospital, luckily we had a fabulous social worker at the hospital that fought her corner and she was able to stay in there until a place came up." A0067 NIECE 1

One study participant expressed deep sadness at his inability to cope with the care burden as his wife's condition deteriorated.

"I was looking after my wife doing the best I could but she was doubly incontinent, well you know what it's like. I was due to pick her up from day care and I just burst into tears and I just couldn't stop (becomes emotional). So they kept her there and I went downhill a bit (emotional as discussing this) but eventually I got a bit better (Emotional)" B0052 SPOUSE 1 HUSBAND

It appeared at some point during the disease trajectory that long term care became inevitable for all the study participants. There was some suggestion that participants often felt regret or guilt that they could not provide the support needed for the person to remain at home. All participants made it clear during the interviews that it was a difficult decision and one they did not want to make.

"In February 2006, XXX was diagnosed with dementia. Two years later he was admitted to the XXXX as his dementia had got progressively worse this was a very difficult and distressing time for the family and he needed 24 hour care and we couldn't cope very well. . He was eventually taken into the XXXXXX. He settled into the unit quite well and the staff cared for him. I could visit anytime and I like to think we developed a good rapport. He began to get physically very frail and he was spending more and more time in bed. He died about six months ago now" A0068 SPOUSE WIFE 3

"A friend of hers is in care homes, she basically knew what was going on; basically she had lost confidence in her home and could not cope. That's why we went with a nursing home, and that's the only reason." B0062 SON 1

4.2.3.1 Finding a Suitable Nursing Home.

All study participants expressed concern over the need to find a suitable nursing home. The most recurrent accounts reported being given a list of nursing homes in the local area by social services and how they had to make the choice for their relative based on little information and experience.

Although there was expressed an inevitability about the need for LTC, for some study participants the previous experiences of poor care in nursing homes increased the level of anxiety. The accounts acknowledge the continued responsibility and duty towards their relatives experience despite being in long term care environments.

"So my mum ended up being shifted around for a couple of years, and each time because of the way she was they just give those loads of drugs. We wanted her to go in a home and so then she got put into a home but she ended

up with a broken hip. Obviously to being left and trying to climb out of the cot bed and broke her hip. She never recovered from the broken hip she couldn't walk. So then she lost her mobility, she had very little speech anyway." A0065 DAUGHTER 1

"We only checked a few nursing homes didn't reckon much to them at all. The care was not met, it was unbelievable really. So really if it's one that can be perfectly, delivered well in a nursing home but it depends on the situation of the staff." B0061 SON 1

The study participants cited a lack of information from social services and other health professionals about what constitutes a 'good nursing home'. The main reason is that they felt too inexperienced to go and look for a nursing home and they emphasised the need to be supported as carers to make this choice. This lack of knowledge and experience was illustrated in the following quotes:

"Well that's it isn't it if you don't know enough and no one tells you so you have to go and research it yourself. As for a care home, I don't know if they can't recommend care homes, social services I mean, but they just expect you to know what is a good care home is. You have to put your trust in these people to care for your aunt and hope for the best. I just wish that social services could recommend places so you at least have a starting point and they should come with you for support so they can point things out to you." A0067 NIECE 1

"In a way you just have to take a chance on what people say is good as I had no idea what was good or bad, you hear such terrible stories about care homes. I was so worried that first time I left him there but the staff were very kind to us both." A0068 SPOUSE 3 WIFE

One husband expressed anger over the frustration he felt trying to get more information. He also found the financial assessment for assistance with paying the independent nursing home fees distressing and 'degrading'.

> *"I eventually got hold of a social worker to come and speak to me and (SW said) well then she'd have to go into a home and you'd have to do a means test. Well I said I can't afford to pay for it all we've only got limited savings so I had to do this means test business. It was a very degrading thing to do. So I went down there with all the paperwork and everything and sat down with one of the accountant's lady and she was very nice she really was. And we went through it and we sorted it all out. But last year the NHS took over the funding of XXXXX because she has deteriorated that much." B0052 HUSBAND 1*

Although the study participants reported difficulty finding a suitable nursing home they did express satisfaction in the current nursing home setting.

4.2.3.2 Participants' View on the Current Nursing Home.

When asked the question what it was that they liked about the current nursing home, most study participants felt that the care staff made the difference. This was often expressed that staff cared for the residents and expressed the importance of how their relative was safe despite the advanced stage of the disease, as evidenced by the following quotes:

> *"On the whole I think I and my family have been as good as you get in a nursing home. The staff appear to be caring and like any other place, when you are not there who knows if they feed them? That's no disrespect intended to the XXX, just you never really know. We haven't seen any signs really that this has happened, just the odd time they have left a drink on a table for her*

and walked off and she couldn't get it etc. We had another aunt in another home and she died of malnutrition for sure, meals were just plonked in front of her and she couldn't eat them, when they came they'd go 'You're not hungry, oh never mind' and take it away" A0067 NIECE 1

"Here she seems that she is clean and fed, she seems happy enough, they get the doctor when needed and always communicate to me when this has happened etc. They seem approachable. The home appears clean enough. Regarding the food, I think perhaps they give things that are difficult to eat for certain patients, but usually it's been okay. I think at the end of the day a unit is only as good as the Manager and we haven't had any complaints." A0067 NIECE 1

Study participants expressed similarities in their experiences of the care setting. Trust in the care setting staff to deliver appropriate care to their relative was an important issue for all the study participants.

4.2.3.3 Trust in the Care Setting Staff.

The personal involvement of the care setting staff in the residents and also their own lives was seen as an important feature of good care in the nursing home. This was expressed in the following quote:

"This was a very difficult and distressing time for the family. He settled into the unit quite well and the staff cared for him. I could visit anytime and I like to think we developed a good rapport. He began to get physically very frail and he was spending more and more time in bed. He died about six months ago now. I was glad he was in the XXX and he died there. I think you have got to have confidence and trust in the care staff to do these plans. You have to be sure they are really putting your relative first and that they treat him as he should be. I think contact with the care staff is important as well. I knew I

could talk to the staff anytime I felt like even if I was a bit upset they would listen to me." A0068 SPOUSE 3 WIFE

Participants specifically expressed the important contribution that good leadership and teamwork plays in the culture of care within the nursing home. Continuity of care staff was expressed as being beneficial to the care of the residents with dementia and allowed them to develop a relationship, as expressed in the following quote:

"Yes I think it was sufficient. I think also with a lot of these sorts of arrangements the leadership was in there, the managerial arrangement. Very good team work. Certainly in terms of Xxxxx yes, she had told me her background some of the other staff had worked there for a while, one of the other things about the XXX was a lot of the staff seemed to do, been around for quite a while, obviously wasn't a high turnover arrangement, you were seeing the same faces all the time. Certain amount of comfort there. Teams operating fairly constantly." A0064 SON 2

When asked if they had confidence in the care staff to deliver end of life care, the study participants expressed an emerging confidence in the knowledge and skills in the care setting staff to deliver effective care within the setting. The following quotes represent different perspectives as one resident had died and the other resident was currently on the LCP.

"During the last few days XXXX was not in pain and appeared very comfortable the staff were wonderful, staff were very kind, staff communicated with relatives and kept us fully informed." D001 NIECE 2

"She (Aunt) is frail now and really entering in this era as I talk to you. It's very upsetting but it is also a relief. We have the care plan in place and I can see the staff write down what they are doing. I don't know if its guilt or what

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but you just have to trust that the staff will care as you would and I am hoping

she dies peacefully and not on her own. The staff have instructions to call us

anytime" A0067 NIECE 1

4.2.4 Summary

The difficulties encountered often began with diagnosis and this was often associated

with a lack of information and a lack of expertise from the health care professionals.

As the disease progressed, a lack of support, advice and guidance was also cited as

additional stressors as all parties tried to come to terms with the increasing mental

frailty of their family member. Admission to long term care was often as a result of a

crisis event and was sometimes a welcome relief as coping with the disease became

difficult. However finding suitable accommodation for the person with advanced

dementia was also problematic and again a lack of advice and guidance added to the

already stressful situation.

4.3 Dialogue of Advance Care Planning

Study participants were invited to describe their experiences and understanding of the

ACP process. The ACP document used in the care setting was from the GSF ACP

document 'Thinking Ahead' (GSF, 2012), (Appendix 15), and also included an

'additional information sheet' from nursing home documentation is additional

information indicated any personal information about the resident and the review

dates and follow up ACP interviews with family caregivers

4.3.1 The Experience of Advance Care Planning

Study participants reported ACP to be a planned, yet occasionally informal discussion

with the senior nurse, particularly in the early stages. Initially it appeared that for

some study participants there was some uncertainty about what ACP was concerned with. The most recurrent account suggested that it was an uncomfortable experience in which participants demonstrated emotion as they recounted their experiences as described in the following quotes:

"Erm, yes, yes, me and my sister had a few meetings with XXXX, to discuss within ourselves, how we wanted things to progress. Erm, I would say, I suppose when she first went in there, we had an initial discussion on it, thinking then really as time progressed, discuss it little bit, really the decline was fairly steady until the last few months really. Didn't want to. Sort of on a week-by-week basis, saying oh no she's gone down a lot, it was a very steady. So it was just as we went along, there were just further discussions. Y'know everything had been discussed well before they got to that stage, of needing to go on the pathway." A0064 SON 2

"I wasn't sure what she meant at first and thought it was some sort of agreement to stop any treatment. But Xxxxx explained it to me that it was to find out what XXX would have preferred at the end of his life. I must say I was a bit upset at first to be talking about this. I did not want XXX to think I wanted him to die but he didn't know anyway. It did feel a bit uncomfortable. Xxxxx suggested I take the form home and talk to my family which I did. During this time XXX became quite ill and deteriorated further, they thought he might have had a stroke. We talked it through with Xxxxx and we all decided that XXX had been through enough and we wanted to discontinue any unnecessary treatment and to just make sure he was as comfortable as possible. A0068 SPOUSE 3 WIFE

All study participants demonstrated a pessimistic attitude towards the ACP discussions. The advanced stage of the disease suggested a contributing factor to this as they acknowledged a need to discuss end of life care.

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"It was to try and decide what would be the best course of action if she became very ill and was going to die. There is no point in pretending that is what they did not mean, although I can see why some people would find this very difficult. I just found that I wanted to get on with it. We talked about hospital; well you know what I think about that." A0067 NIECE 1

"I think she just came out with it, because she knows she can. I think if it had been a different family she would have done it differently. But because she knows she could with us she was comfortable enough to do that. And like now Grandma's been sleeping more and more and the staff let her sleep, don't wake her up, don't wake her up to feed her just let her sleep." C0053 GRANDDAUGHTER 1

4.3.1.1 Family Discussions

Participants expressed how they had consulted or informed other family members prior to completion of the ACP. This suggested that other family members were consulted and this was viewed as important, particularly when other family members were available and may be included in future care decisions, as the following quotes suggest:

"Oh yes, I don't think it was sort of totally cast in stone I think we all erm, members of the family felt that we had sort of reached a communal decision which we felt was right for mum, I think as things progressed I expected it, other than the length of time that she carried on in her case seemed to be, she seemed to survive a lot longer than everyone was expecting." A0064 SON 2

"XXXX spoke to me about it. I think it is a good idea that she dies in the care home. We had a family discussion and she sort of knows the people there. Xxxxx is able to care for her and speak to her, whereas the hospital won't

know her. We did not want all tubes and all that sort of thing. ACP is a good thing to happen. " B0051 BROTHER

Participants also felt that as the identified next of kin they should have the final say about what was in the ACP. One husband cited a difference of opinion that may cause disagreement in the future, as described in the following quote:

"Erm it's a euphemism advance care planning it means what do you want to do when she dies. So I have five grown up children and I told them all this is my decision not theirs. Coughs (emotional) we have one son who cares a lot for his Mum (becomes upset at this point very emotional crying). If we let him he would prolong it and prolong it and I don't want that. I told them I had got the form and exactly what it was and what it was for and told them this was my decision. And the reason I said that was that some future time Mum was going to pass away and I am not having you saying we should have done this and we should have done that (becomes upset) it's my decision." B0052 SPOUSE 1 HUSBAND

The ACP was viewed as necessary but that it was dependent on the care setting staff to deliver the agreed care in the future. Continuity of care within the care setting was identified as a prerequisite to facilitate the implementation of the ACP.

4.3.1.2 Continuity of Care

There were some concerns expressed about how this 'plan' would be put into practice. Variations in nursing staff and inconsistencies in care provision either currently or previously in other care settings, appeared to contribute to some concerns from study participants. An example of this is expressed in a quote from a family member below.

"I was invited in for this process and we went through everything. They took the lead off me as I am a very matter of fact and so we dealt with it in that way. But my feelings are that no matter what you discuss or put down on paper, it's all down to the staff at the end of the day, if they have enough, if they care enough, if they have enough experience etc. We sat down with an 'action plan' type thing and went through it." A0067 NIECE 1

These anxieties were particularly expressed regarding care at the end of life and if the plan was going to be followed by all those involved in the residents care. This concern is described in the following examples:

"I think it is applicable for nursing homes especially as they care for so many elderly and frail people so they deal in it all the time. However once again, I think it's down to the staff. You can have all the written items but it does not mean they will be referred to. I don't know if it's guilt or what but you just have to trust that the staff will care as you would and I am hoping she dies peacefully and not on her own. The staff have instructions to call us anytime." But my feelings are that no matter what you discuss or put down on paper, it's all down to the staff at the end of the day, if they have enough, if they care enough, if they have enough experience etc." A0067 NIECE 1

"At the end of the day it's their job, they're not there out of love. And I'm not able to do it, otherwise we'd have her here (home), but I just couldn't do it." A0065 DAUGHTER 1

Furthermore one daughter expressed concern over the night staff and to what extent they knew their relative and took an interest in their care.

"Whereas the night staff, all they have to do is get them to bed and change them in the night, so there isn't really the interest, and maybe they don't really have the compassion." A0065 DAUGHTER 1

There was also some suggestion from participants that potential conflict between professionals may also present as a difficulty in facilitating the ACP. The following quote from a son expresses this view about GPs.

"All things seemed to work OK in mum's case, I don't know whether it's a mistake if perhaps you were dealing with a GP and they weren't of the same feeling about end of life and whether there would be some conflict. Everybody seemed to be of the same thoughts; it might be different if they weren't singing from the same hymn sheet." A0064 SON 2

As well as their experiences of ACP, participants were also asked about the relevance and appropriateness of this to people with dementia.

4.3.2 The Relevance of Advance Care Planning for People with Advanced Dementia

There was general agreement from all study participants that ACP was appropriate for people with advanced dementia. The participants offered a compelling argument that it was important for relatives to be involved in end of life care discussions as they try to represent the views of their relatives within the ACP. Despite their obvious distress during their recollections of the ACP discussion the study participants welcomed the opportunity to be involved in end of life care decisions as they felt it was their responsibility as the person was very vulnerable and in need of protection.

"XXX left his funeral instruction in his Will which he made years ago when he was first diagnosed so we knew what he wanted but it was good that the staff asked and were interested to know those details. I think the advance plan or care plan is good for people with dementia otherwise everybody just guesses what the person wants as they often cannot speak. My XXX could not talk or communicate towards the end he just smiled sometimes and looked lost." A0068 SPOUSE 3 WIFE

There was general agreement from all study participants that in view of the previous difficulties with diagnosis and a lack of information about the disease trajectory they welcomed the opportunity to clarify what was to be expected as the resident deteriorated.

"I would say, it removed a lot of the uncertainty, that perhaps hadn't the advance planning been done, all of a sudden you'll be faced with a decision, it would be at a time perhaps when you're not emotionally not prepared for it, and it would be a bit too much at that stage. At least if you've planned it, I thought it helped, in my case, I discussed what was going to happen, how best end of life can be dealt with in terms of making her life as easy as possible really." A0064 SON 2

Several participants expressed a view that ACP discussions were an opportunity rather than something negative. Participants suggested that it allowed them to confront important and inevitable decisions that had to be made as the resident deteriorated. The following quotations represent this view.

"Personally I think it was a very good way of going about things. It forces you to confront various things that you need to address. Perhaps if you don't, it can make a poor decision later when you more wound up, things around you haven't thought about. At least if you've planned it, I thought it helped, in my case, I discussed what was going to happen, how best end of life can be dealt with in terms of making her life as easy as possible really." A0064 SON 2

"One thing the advance plan has done is that it has given me the opportunity to really think about my aunt and what she was like. How she would think of how things have turned out and if she wants to be kept alive for as long as possible. I don't think she would want this but I suppose I can only do the best I can and hope I am doing the right things and making the best decisions, but really no one prepares you for this burden." A0067 NIECE 1

The most frequently cited issues by the participants relevant to people with dementia, were the concern over communication difficulties.

"XXXXX would not have liked a religious minister to be present when he was dying but he could not say this, but I know him during the advance care planning it gave an opportunity to discuss such matters with XXXXX" D002 WIFE 2

"Dementia unfortunately is one of those things, unless there's a hint of body language you've no way of communicating with someone, so you've really always got to second guess what's going on." A0064 SON 2

4.3.2.1 Anxiety During the Advance Care Planning Discussions

Study participants did express that ACP did cause personal anxiety about if they were doing the right thing. Although participants reported that it was very useful to

undertake these discussions to make sure the person's interests are supported, they often expressed some doubt or apprehension and welcomed the opportunity to review the care plan at intervals. This doubt was more likely to be expressed by extended family members.

"I felt like the parent deciding what's best for the child. It was uncomfortable as you decide what the right thing is but in the end I don't want Aunt to suffer any more than she has. We talked about if withholding treatment would make her suffer. XXXX was very good and gave a range of scenarios and what we could do and what we could do make her comfortable. I can only do the best I can and hope I am doing the right things and making the best decisions, but really no one prepares you for this burden. I don't know if it's harder for me as her niece or easier. Who knows? She (Aunt) is frail now and really entering in this era as I talk to you. It's very upsetting but it is also a relief." A0067 NIECE 1

"I wonder about doing the right thing as I did not have a lot of contact with her up until she became ill so I try and think about what she would have wanted when she was younger or what I would of liked. I also think about how our parents died. I suppose you just have to do the best you can." DOO3 BROTHER 1

"It was a care pathway but it wasn't concrete, it can be flexible, can come off it for a few weeks then go back on it. When that was explained some of the tension was removed a little bit. Then she went worse and it came to the end of life – this advance plan and it hit me, hit the end of life button that's when I rang up my brother then, he felt we had signed his mum's death warrant really. When you see things written down." B0061 SON 1

Two participants expressed the benefits of the Lasting Power of Attorney (LPA) in the early stages of the disease.

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"And another thing someone gets diagnosed with Alzheimer's, and then there's a booklet get books, go on the internet like I did and PLAN your life. One of the first things they advise is to go and get an enduring power of attorney out so I was grateful about that. I have told my children all along about everything that has happened. The only thing I won't let them interfere with is the end of life form which is what is what it should be called." **B0052 SPOUSE 1 HUSBAND**

"I think the main thing really is planning the whole process, in the early stages, who'd you go to for advice? And also it's what your rights are in a way. I'd ask myself before she went into the home that we'd got power of attorney over her care, and that did help." **B0061 SON 1**

4.3.3 Content of the Advance Care Planning Interviews

Study participants repeatedly reported what the content of the ACP included. Similar responses referred to the care at the end of life and what would or should happen if the person deteriorated and was now considered to be dying. Participants also expressed that where treatment is futile the resident should not be distressed by active interventions. Active interventions were cited as tube feeding, emergency procedures and hospitalisation. There was some suggestion that advanced dementia was viewed as a terminal condition and worthy of end of life discussions during the ACP process, but this was not always identified specifically by study participants, during the interview.

"We talked about drips and tubes and pain relief. XXXXX was as blunt as she could be without making it sound as though she was trying to influence our decisions. We talked about if withholding treatment would make her suffer." **A0067 NIECE 1**

"I think there was a reasonable discussion about the physical side effects, when it got to the stage where she (Mum) refused food or fluids, what would happen and such from a physical point of view. And then what can be done from a medical point of view without obviously horrendous intervention. How pain relief can be used, other drugs were mentioned, calming and all this sort of stuff. It was a bit heavy towards the end and more discussion about that side of things." A0064 SON 2

Frequently the study participants expressed the benefits of being able to have open and honest discussions with the care staff, in particular the senior nurse with whom the ACP discussions had took place. The following quotes are examples:

"So they know how I feel and sometimes I find that quite revealing to wish your parent dead. I can't stand to see her so weak." A0065 DAUGHTER 1

"It's a bit like a family but well obviously not to the same extent .. but it's a caring environment. I think it does there has to be some trust because they are looking after someone so precious to you you got to trust them to do it properly like you would do it yourself and when we have said she likes this she doesn't like that they have listened. I see XXXX more than the others, she's my main port of call ..it's just the way she interacts she does not force her to get up or get up get out of bed to go and watch telly for the afternoon .. she lets her do what she needs her to do." C0053 GRANDDAUGHTER 1

4.3.3.1 Euthanasia

One daughter expressed a desire for her mother's condition to end and that she had suffered enough. She expressed support for euthanasia and a need to end the suffering of her mother. In the absence of euthanasia this account appears to

represent the distress and anxiety that this relative felt and her experience of the dementia disease trajectory.

"Yes ...now to me that (the ACP) means palliative care. With XXXX, it was lucky because she knows how I feel , I'll go and I'll talk to them and I'll tell em, she shouldn't be here... then pray to god it comes to an end, I want it to end for my mother. She was a good mother... let her go in peace. She discussed about medication, how it would go, would I want her to go to hospital. All I want for my mum was to not be in pain. Personally I would like a doctor to give an injection, but they won't do it. And like I said if she gets a chest infection or anything like that, they will phone you and talk it through with me. She always gets antibiotics. Me personally I'm at the stage now where if she didn't get antibiotics and she'd get pneumonia and that would kill her off, and I personally would go down that path." A0065 DAUGHTER 1

This same daughter, despite being distressed, also expressed a concern about the attitude of some health professionals and how they may still be willing to treat acute illness even if the resident would be considered to be dying.

Well ....withholding treatment which is not what they do. It's like there's a whole system that don't want to do anything about it, or are frightened to death of it. For me... I love her to bits, love her that much that ... give her an injection... I'd give her injection tomorrow ... if I thought the law was on my side .... I'd give my mum that injection, and I know hand on heart that I would have no regrets, and I know that I would have done the right thing. Because she has no quality of life." A0065 DAUGHTER 1

There appeared to be some concern from this relative about what end of life care may represent and this may indicate a lack of understanding of palliative care outcomes.

4.3.4 Summary

ACP was reported by participants to be a planned discussion between the study participants and the senior nurse on the unit. There did not appear to be any fixed time frame in which the discussion took place nor did there appear to be any 'set' model of how the discussion took place. All participants reported a different approach to the introduction of ACP discussions. This may have been deliberate on the part of the senior nurse and did suggest that sensitivity was appreciated when introducing ACP with relatives.

4.4 Care at the End of Life

Six residents died during the study period. The study participants of all five residents were asked to describe the experience and care in the last few days before their relative died. Generally all study participants were satisfied with the end of life care arrangements for their relative. All felt that they were part of the end of life care discussions and decisions and were kept informed by the nursing home staff.

> *"He went on this care plan and in the end it was all very quick and quite sudden. XXXX had gone through the care plan and we talked about options such as medication, fluids and hospital. I did not want him to go into hospital he would have hated that. The plan they had took all his wishes into consideration. He had fresh flowers in his room because he loved them and the staff made sure he was kept quiet and comfortable. He was visited by the minister and we all had a little prayer at his bedside including XXXX. I don't think anything could have been done better." A0068 SPOUSE 3 WIFE*

One study participant (wife) was eager to stress the importance of after care for the family and suggested the need for bereavement care following the death of the

resident. The experience of having dementia in the participant's life for so long is clearly expressed in the following quote:

"I think contact with the care staff is important as well. I knew I could talk to the staff anytime I felt like even if I was a bit upset they would listen to me. I think there should be some follow up bereavement care. Having had this disease as part of your life for so long it suddenly leaves you a bit lost. I have been back to the XXX since XXX died and they have been very good but it's not the same and it brings back some painful memories. But I know I can go and see them if I want to." A0068 SPOUSE 3 WIFE

An understanding of the need for a 'care plan' to guide and inform care was understood by the participants and allowed them to be involved in the end of life care of the resident.

4.4.1 Care Pathway

Study participants expressed a readiness for the death of their relative, for which they were not always prepared. The ACP was seen as a precursor to the end of life care pathway once it was acknowledged that the resident was in the dying phase. The end of life care pathway appeared to be initiated by the senior nurse. Participants acknowledged the sensitivity and support from the care setting staff during the dying phase, which the following quotations demonstrated.

"It really hit me the hardest, ... before....nothing really prepares you for that does it? XXXX and the staff were very supportive and helpful. They understood. It was all praise for everything we got from them really. Staff were very good. They had this care plan this document. All along we were

advised what to do, about nursing care etcetera, reviews on nursing care, and we were involved in that as it came." B0061 SON 1

"Auntie's condition deteriorated rapidly over seven days and she died peacefully and at 'home'. The staff made the difference, they knew her very well and were like part of her family....some came to her funeral. The care pathway was very useful and gave me an opportunity for open discussion with the staff and if she had any special requests; a CD player was put in her room so it was not so quiet. She was not in pain and appeared very comfortable and the staff were wonderful and were very kind and kept us fully informed."
D001 NIECE 2

The participants reported how the care pathway influenced the physical care of the resident, but also the personal needs and wishes that were important. This suggests that end of life care planning included physical as well as person centred goals. Dying in the nursing homes appeared to be facilitated, rather than the resident being transferred to hospital for palliative care.

4.4.2 Hospitalisation

The role of the hospital for delivering palliative care to their relative was expressed in all cases as something that should be avoided. All had expressed, during the ACP discussions that they would prefer their relative to die in the current care setting. There were several concerns that were identified during the interviews relating to the issue of hospitalisation and this included the previous experience of hospital care, staff training and education in dementia and the lack of time to adequately care and meet the needs of people with dementia.

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"One thing I would say is that the end service is about making sure if we are called to her there's someone there rather than in a big hospital. That's about it I think yes. We discussed it and said that the answer would be no and it would have to be a last resort. In a home rather than in hospital. We felt she was looked after, and they could look after her far better than the hospital could. They wouldn't have been able to give her the 24 hour attention she required. That's right with hospital staff you get different staff, no same person looking after them. Rather she's around people who've looked after her since day one. The continuity in the home was fantastic really. Because you know who to talk to and we knew we could ask how she is today. What sort of shift has it been like? That sort of thing. That was very good." B0061 SON 1

"In March mum's condition deteriorated rapidly and we (the family) were called to the home. Again the end of life care pathway was confirmed. We did not want mum to be transferred to the hospital or given any other unnecessary interventions. We wanted mum's final hours to be in an environment she knew surrounded by the people who loved and cared for her." D004 DAUGHTER 2

The avoidance of hospital to enable good end of life care was expressed by all participants. Participants often expressed this vociferously as indicated in the direct quotes included above.

4.4.2.1 Previous Experience of Hospital Care

Study participants expressed concern over their previous experiences of hospital and nursing home care. A lack of time, knowledge and understanding of the needs of older people were cited as the main barriers to good care in these settings. Examples of this are demonstrated in the following quotes.

"They did not care; they had no time for a confused old woman. She was in the way and she was sometimes a bit difficult to manage. Not because she was aggressive but because she was confused and didn't know where she was some of the time. The staff did not know how to care for people with dementia. They need more training and a better attitude." A0067 NIECE 1

"I think it would be the actual level of care that she would get. Over the last few years she has been in hospital, and really I think the nursing staff in hospital are under more pressure, they've got so many more other things to do. There is not the level of attention to an elderly person that can be achieved that in a nursing home environment. I don't think the hospital staff have got time to get on board with that, really we found less and less staff, unless there was a dire emergency that (hospital) was the last place we wanted her to go." A0064 SON 2

"I don't think that would happen on a hospital ward as they are too busy. Staff in the care home know them better they see them more often 24/7." A0068 SPOUSE 3 WIFE

The previous experience of how the resident had experienced hospital care was an influence on their attitude towards end of life care. Their main concern was the lack of understanding of the needs of older people and particularly those with dementia. A perceived deficit in the education and training of hospital staff was cited by several participants.

4.4.2.2. Staff Training and Education

There were similarities expressed by participants suggesting that hospital staff did not have sufficient training to meet the needs of older people, particularly those with dementia. They expressed a preference for the skills and knowledge of the nursing

home staff who they felt had an affinity for the needs of people on the specialist dementia unit.

"Here at the XXX the staff are more trained to care and look in on her often. If she was taken into hospital they would put her into a bed and if the nurses have got time she is lucky if they might look at her." B0052 SPOUSE 1 HUSBAND

"I don't think they could deal with her mental state. My grandma has never felt pain apart from having my mum, up until then she has never broke anything just never hurt so she doesn't handle pain very well, (laughs), sweet thing she is, she's lovely but they could not handle her." C0053 GRANDDAUGHTER

Participants felt that the nursing home staff could meet the end of life care needs of the resident with dementia, despite the lack of 24 hour on-site medical care. The nursing homes had access to doctors within a General Practice and the out of hours medical services, who may or may not have known their relative in advance.

4.4.3 Role of the General Practitioner

None of the study participants had an ACP interview with the GP. Only one participant reported discussing end of life care with the GP, and this one study participant reported this discussion when their relative was dying in the nursing home.

"The GP visited mum (in the nursing home) and provided information on pain relief and confirmed that no medical interventions other than those to promote comfort would be implemented. Mum died peacefully....with her family

around her. The pathway supported mum and the family to ensure she died in the home and not in a hospital ward surrounded by nursing staff who knew nothing about her." D004 DAUGHTER 2

The participants who reported no contact with the medical staff suggested that two issues related to the role of the GP. The first issue related to how necessary the study participants felt there was a need to involve the GP and secondly how the attitude of the GP may influence end of life care. This is illustrated in the following quotes:

"The staff kept us informed and involved us in his care. We did not have an opportunity to talk to the doctor but I don't think that mattered. I was not really bothered about talking to the doctor. We got enough information from the care staff." A0068 SPOUSE 3 WIFE

"No there doesn't seem much point. We have had the opportunity to talk to them if we want but I didn't. I don't want them doing any unnecessary things like tubes and drips if it is not going to do her any good. I think doctors can have a different attitude than nurses, or maybe not. I don't know." A0067 NIECE 1

GPs were generally viewed as providing additional treatment for physical care, which may or may not include invasive interventions. Personal or person centred care was provided by nursing home staff who the participants felt knew the resident very well.

4.4.4 Spiritual Care

Study participants often referred to personal matters when discussing the care during the dying phase or to justify the ACP discussions. The study participants reported that they did have the opportunity to talk about the individual as a person and how

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they lived as well as what they would have wanted at the end of life. The personalisation of the ACP indicated a need to discuss a spiritual essence of care, but not necessarily in the context of religious practice (Jeong, *et al.* 2012). This was reported as an opportunity provided by the senior nurse on more than one occasion, suggesting a staged discussion and an interest in the resident in order to facilitate ACP discussions.

> *"Alzheimer's is a monster of a disease ....any intervention that can help in any way is welcome. The relationship a resident has with the care staff is very important they need to know who the person is and what they did or achieved in their life." D004 DAUGHTER 2*

> *"My aunt's condition deteriorated rapidly over seven days and she died peacefully and at the 'home'. The staff made all the difference, they knew her very well and were like part of her family....some even came to her funeral." D001 NIECE 2*

All study participants referred to the loss of the person with advanced dementia. It was important to remember them as a person and not just someone with dementia. This was expressed as what was meaningful to the resident even though they were unable to communicate. Participants accepted that death was to be soon and expressed a desire for it to come sooner rather than later, but also expressed a need to make sure the personal history and personality of the person is kept alive to the end. Although none of the participants initiated a spontaneous discussion about the meaning of religion in end of life care, some included the personal preferences in respect to religion and religious practices.

"We have been saying goodbye to grandma for over 10 years because my grandma's gone! You get little glimpses of her but she's not there anymore. You know? She doesn't play her music anymore she doesn't play her Black Sabbath at full volume and dance round the kitchen like she use to .. and that's at 80.. she can't get on the back of the boys bikes anymore .. "she's not there". Which is sad." C0053 GRANDDAUGHTER 1

"He had fresh flowers in his room because he loved them and the staff made sure he was kept quiet and comfortable. He was visited by the minister and we all had a little prayer at his bedside including XXXX (senior nurse). I don't think anything could have been done better." A0068 SPOUSE 3 WIFE

The maintenance of the image of the whole person to keep alive their personal history, was expressed as being very important by study participants. An important feature for participants was the relationship that they and the resident had developed with the care staff in the nursing home.

4.5 Future Priorities

All study participants were asked if they could suggest improvements in health and social care services for people with dementia and their relatives and carers. Referral to a range of support services for advice and support was also reported as important for monitoring and selection of treatment options. Study participants also expressed an urgent need, often intensely, to educate and train carers about people with a diagnosis of dementia in practical skills and behaviour management techniques to ensure they are adequately prepared for the disease as it progresses.

"I think anybody who is diagnosed with any form of dementia not just Alzheimer's, Lewy bodies, dementia from blood flow, anybody whose diagnosed with that it should be notified immediately to social services, Help the Aged, I mean anybody who they think could help. I really think that there is a need for some form of counselling for the carer because it is a tremendous, tremendous burden. Don't get me wrong I love ... (becomes upset). By golly gosh it would." B0052 SPOUSE 1 HUSBAND

"I just wish it was not all down to luck or chance if you get good quality care with dementia. You are so reliant on others to care for this person and you can't be there all the time. You rely on the goodwill of others and hope they have the skills and attitudes to really care. I mean really care not just because they get paid for it." A0067 NIECE 1

The recommendations for improvements which all participants suggested were based on their previous experiences of the dementia journey and following the death of their relative. A recurring theme was the need for early diagnosis and adequate inter-professional cooperation and competence in dementia care.

4.6 The Deviant Case

One deviant case was identified (C0055 Wife 4) who was the wife of a resident in the care setting. The reason why this case contrasts the others is that during the interview her viewpoints and responses differed with the majority of the study participants. Rather than set aside her view as different, it was important for the purpose of relevance and validity, that her understanding and experience was reported (Silverman, 2006, 2010).

This respondent contacted me by hand written letter following initial contact (by letter) and gave her telephone number and details of when I should contact her to arrange an interview. Once an interview was arranged she invited me to come and talk to her in her home. It was very clear on arrival that this study participant viewed my questions as an opportunity to complain about the care services (I had come to listen to her problems) and she wanted to discuss this. Despite the need to remind her on several occasions the purpose of the interview she did not appear receptive to this information.

The interview commenced with the same question by asking why her husband was in the care setting and to include something about his personal history. I received a very lengthy account of his work history and life prior to the entering of the nursing home. I prompted several times to ascertain why her husband had been admitted to the care setting, eventually she cited several falls in which he sustained injuries but she did not accept it was the result of the dementia and his failing mental and physical condition.

> *"XXXX (husband) started falling, quite a lot and he's had quite a few injuries, I had to keep phoning the ambulance, of course then at this particular time was horrible, he came out of that bathroom, and he'd slipped and he'd smashed his face against the base of the bed. And he'd cut his head right across and it was gaping open, you could see the bone." C0055 WIFE 4*

This then allowed for a discussion on his present whereabouts and why he was admitted to the care home. When asked to tell her story of how he was admitted and her experience of the care setting she responded in terms of what she had done or how misplaced her husband was in the specialist dementia unit (at no time did she refer or acknowledge this care setting was a specialist dementia unit).

"Yes. I think they put him there, only my opinion, I think, because of his constant falling, and he did fall a lot and he had some terrible injuries". C0055 SPOUSE 1 WIFE

This participant did not acknowledge that her husband had dementia, yet the description of his confused behaviour would suggest otherwise. She blamed the care staff and doctors for failing to put her husband's best interests forward and that he had deteriorated as a result of being in the nursing home. She was very critical of the care home staff and the attitudes of some staff including the senior nurse. However she did not offer any alternative example of where she felt he should be cared for.

"I went to see him yesterday, I was amazed, he'd pulled the side off his chair and he'd taken his brakes off. And I said what are you doing? He said I want to get out, those were his words. So he's thinking not like the others and he can't speak very well, he said it straight away I want to get out. He's asked about XXX, that's my son, and he's asked about XXX (daughter) and he's not seen her for years. It's amazing, and the one he did see a lot of XXX (daughter) he never mentions her. Strange." C0055 SPOUSE 4 WIFE

The study respondent talked about her feelings of inadequacy and being under pressure to care for her husband at home and cited her step children as being not as supportive as they could be and this was a reason why she could not take him out of the care home.

"They (step children) think I'm capable of anything and everything and I'm not and they don't realise. I said can you put some oil in my car because I can't get the bonnet up because it's too hard for me because I've got osteoporosis and can't get up stairs. Oh they said you've done it before mum I said I can't do it, and they said, ohhh get someone to do it for you. My

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children (step children) they are very independent and they have always worked so they are capable of anything and they think I'm the same. And I'm not. Ha ha ha ha. Mind you I had to change my curtains the other day because I've lived here four years and I've not changed the curtains, I put those up the other night and I had to get the ladders out I was a little bit wobbly but I did them! I did do it; you know you've got to do it. Because like I say they all work. And they work hard, got three, got two of them, one lives in XXXX somewhere and one just lives across town and I see him more than anything.
C0055 SPOUSE 4 WIFE

Interview questions that related to the role of the GP and the support offered was greeted with some anger by the respondent. This appeared to be the result of the decision made by the hospital doctor for her husband to remain in hospital and eventually be transferred to the nursing home.

"Doctor XXXX came, our doctor, and she said you know, you've got all this heart trouble, you've got osteoporosis. She said I think he needs to stay in hospital, because he needs to get his strength up. I said oh I don't know about that and she said he needs to stay in hospital and be looked after properly and she phoned the hospital, and I'll always remember her doing it, and he wasn't well. Anyway she was looking at me the doctor brazen like, well from the hospital he went to the XXXX." *C0055 SPOUSE 4 WIFE*

A different GP was allocated that served the nursing home and this also caused some anxiety for this study participant.

"Well I mentioned this yesterday, I said I wasn't even asked what GP I wanted for XXXX (husband), so she said XXXX's GP wouldn't have come all this

way. I said how'd you know, you never asked him. I know people who live in XXXXX and they go all the way across town. She said oh I think all that's changed now. I don't know whether it's changed or not, it may have done. I don't know, you can't argue with something like that, you've no answer."
C0055 SPOUSE 4 WIFE

Documentary evidence within the nursing notes suggested an ACP had been commenced with this study respondent, however she was very reluctant to discuss this issue. She did not appear to embrace or accept the purpose of an ACP and the relevance of this to her husband's advanced stage of dementia. Her husband had been a resident in the nursing home for several months, but the ACP discussion had only been commenced three weeks prior to the interview for this study.

"Oh that (ACP), she tried to say it was some scheme they were involved in and that I needed to talk about what XXXX would want if he became very ill. He is going to get very ill if he stays like this. I don't know what she was talking about . I think XXXX is getting depressed in there. I don't want to talk about it, that would be like giving up and I haven't given up. C0055 SPOUSE 4 WIFE

Despite several attempts to discuss the ACP the study participant was not receptive and therefore there was no ethical and justifiable reason to continue with this level of questioning. The interview lasted 90 minutes without discussing the issue of ACP that could contribute to the study objectives. The interview was terminated and evolved into a social encounter in which the study participant discussed her hobbies and interests at some length.

This deviant case highlights the request for a story that needs to be heard. It was important that the study participant was given an opportunity to display that she (wife) is still an adequate carer or loving wife to her husband. It also highlights and considers that despite her husband's deteriorating condition due to dementia, she was in denial about his impending deterioration and not ready to discuss this or end of life issues.

4.7 Summary of Chapter Four

The findings indicate that study participants acknowledged that a lack of knowledge, skills and understanding of the disease trajectory of dementia contributes to their anxiety and issues with the aspect of the dementia journey from diagnosis, admission to long term care and in the advanced stage of the disease until death. This was compounded by a lack of a coordinated approach by all health and social care professionals and a lack of referral to specialist services and health and social care services early in the disease trajectory. The crisis events that led to admission to long term care often resulted in a need to find suitable accommodation that was not always planned for.

A lack of support and guidance by social services on what constitutes suitable nursing home accommodation for someone with dementia was indicated by participants as being particularly stressful. The lack of experience of nursing home care and the time involved locating an appropriate setting was cited by family caregivers as being problematic. Satisfaction with their eventual decision of the current specialist dementia unit was indicated by the reporting of the communication skills and

knowledge of care staff, the continuity of care from a stable workforce and trust in staff to treat their relative as an individual.

This trust in the nursing home staff, as reported by the family caregivers, allowed for the ACP discussions to be facilitated within the care setting. Participants reported a planned, occasionally informal and staged process, lasting over several weeks in some cases. Participants did not express any view that the ACP would hasten their death or that care setting staff had any ulterior motive for not treating acute illness. They did express a realism of the need to discuss end of life care issues, due to the advanced stage of the disease, with reluctance and regret to dealing with a situation that required this. They also expressed their distress and discomfort (often expressed by crying) during these discussions and decision making, and how making the right decisions were important with or without other family members input. This was often expressed in terms of their previous and current role and relationship with the resident with dementia.

Participants expressed the value of the ACP discussions with regard to opportunities to discuss the resident and their history, prepare for the inevitable end of life care and discuss treatment options and interventions as the disease progresses. There were some reservations about how the ACP would be followed by those participants whose relative was not on an end of life care pathway; however those participants whose relative had died were satisfied that care was delivered individually to their relative and met the arrangements as discussed in the ACP.

Only one participant expressed a desire to purposely end the life of their relative. However this was discussed in terms of an expressed lack of dignity of her relative and also as a means of expressing emotional distress.

ACP discussions also included the potential of hospitalisation if the resident deteriorated and this was viewed as an important and essential component of the plan. The views on the avoidance of hospitalisation and the ability of hospital staff to adequately care for someone with dementia were consistent amongst all study participants. Previous hospital experiences were the main focus for this belief and all participants cited one or more of the following: the lack of time for hospital nurses and other care staff to meet the complex needs of their relatives; the lack of dementia care training and knowledge; and the general negative attitudes of care staff to older people.

Spiritual care, although not specifically referred to, was expressed by some in terms of the importance of the person in the context of their life histories. This was viewed as important to maintain the good memories they shared with the resident and how they could make appropriate decisions based on the wishes of their relative. Trying to do the right thing was expressed often in terms of what their relative would have wanted. This view appeared to give support to their decision making. Religious beliefs were not raised as a spontaneous discussion despite the discussion on end of life care needs.

The 'deviant' case identified a contrasting viewpoint on the experience of the care setting and the readiness of family carers to discuss issues of dementia, ACP and end

of life care needs. The lack of acknowledgement of the diagnosis of dementia and why the resident was admitted into a specialist dementia unit was a barrier to ACP discussions. This case demonstrated role conflict and contributed to the feelings of a lack of trust and poor communication between the participant and the health and social care professionals.

The following chapter five draws together a detailed discussion of the results from study on the experience of family care givers when undertaking ACP. It compares and contrasts the findings with the research evidence and policy literature as well as discussing the study objectives and the limitations of the studies. It also includes the implications of the findings for policy, practice and research and a personal reflection of having undertaken this research and implications for research involving vulnerable adults on sensitive topics. In chapter six, conclusions are drawn and key recommendations made for policy, practice and further research.

Chapter 5: Discussion

5.1 Introduction

This chapter includes a detailed discussion of the findings from the results of the study of the experiences of ACP with family caregivers. It also includes a return to the literature, a restatement of the study objectives and how they have been addressed and the implications of the findings for policy, practice and research. The discussions with family caregivers and care setting staff undertaken in this study are also presented here as a composite case for consideration. The composite case will attempt to go beyond the descriptive data and attempt to attach significance to what was found to try and make sense of the findings and consider meanings (Patton, 2002).

There has been increasing attention paid to the experience of dementia over the last decade. This is in part due to the anticipated rise in the numbers of people who will be diagnosed with the condition. The WHO describes this situation as a public health priority and acknowledges that people with dementia have been repeatedly failed by governments and communities throughout the world (WHO, 2012).

Ouldred and Byant (2008) describe the diagnosis of dementia as being 'devastating' not only to the individual but also to their family and that early assessment and referral is very important to the whole dementia experience. A National Audit Office (NAO, 2010) report estimates that only one third of people with dementia are formally diagnosed. Fear surrounding a diagnosis of dementia may delay older people and their families from seeking help and advice which is recognised by the WHO (2012) as being problematic and suggests that the stigma associated with the

public perception of dementia should be addressed through education and by raising awareness. The stigma associated with the 'demented' has negative consequences for the sufferer and their family (Bartlett and O'Connor, 2010; Werner, *et al.* 2012). Werner, *et al* (2012) suggest that the stigma associated with having a family member with dementia can impact negatively upon the caregiver experience and may impact upon caregivers seeking help and support which may precipitate premature nursing home placement. These difficulties associated with dementia have been acknowledged by the British Government who suggests that the creation of 'dementia friendly communities' may help to improve understanding and support (DH, 2012:4) and improve standards of care.

Guidance from the National Institute of Health and Clinical Excellence (NICE, 2006) emphasised the need for prompt diagnosis at an earlier stage of the disease. Earlier diagnosis would, according to the NAO (2007), exclude reversible causes and allow earlier access to services and therapeutic interventions for people with dementia and their family caregivers. The main priorities as recommended by NICE, (2006) also included, emphasis on carers' needs, coordination and integration of health and social care services, early assessment and a single point of referral, and dementia training for all staff working with older people. WHO (2012) also suggests that the key role of family caregivers is often neither supported nor properly acknowledged and that there is an urgent need to improve the awareness and understanding of dementia across all sections of society. In July 2012 an all party parliamentary group on dementia recommended that public health directors across the UK should make early diagnosis a priority and that all health and social care professionals should have pre and post

registration training in identifying and understanding dementia (House of Commons All-Party Parliamentary Group on Dementia, 2012).

Dementia has only in recent years been accepted as a terminal condition and worthy of palliative care in the later stages of the disease (NICE, 2006; DH, 2009). However, difficulties remain with the acceptance of this amongst health professionals who often act as the gatekeepers to palliative care services (Care Quality Commission (CQC), 2010). Mortality rates associated with dementia, from diagnosis can range from 1.9 years to 7 years (WHO, 2012; Rait, *et al.* 2010). People with dementia often have at least one other co-morbidity (WHO, 2012; NAO, 2007) and it is often this that is cited on death certificates (WHO, 2012). WHO (2012) reported that death certificates are unreliable as dementia is rarely considered as a direct or underlying cause of death (WHO, 2012). Dening, *et al.* (2012) identified five areas that need addressing to provide good end of life care; impact of hospitalisation; care pathways; ACP; impact on carers; staff skills and training.

In the UK dementia is a major reason why a person may receive institutional care (nursing and residential homes) as approximately one third of people with dementia live in a care home (CQC, 2010; DH, 2009; NAO, 2007). In recent years the provision of palliative care in care homes has been the focus of national and local initiatives (DH, 2011b; DH, 2009a; DH, 2006b). The Department of Health End of Life Care Strategy attempts to apply three approaches to deliver palliative care in non hospice settings including care homes; The Gold Standards Framework (GSF); Liverpool Care of the Dying Pathway (LCP); and Preferred Place of Care (PPC) (DH, 2008). Prognostic indicators for dementia have also been developed as part of the

GSF to guide health professionals in recognising the last year of life (GSF, 2011; Thomas, 2010a) so as to encourage initiation of palliative care earlier in the disease trajectory.

PPC is a document which emphasises patient choice and ACP (DH, 2008). In dementia, ACP provides an opportunity to anticipate future decisions relating to health and care needs as eventually the person loses capacity and will be unable to make their choices known. It also provides an opportunity to initiate timely palliative care in life limiting conditions (DH, 2011a) and consider the alternatives to long term care. However an ACP is often not initiated early enough in the disease trajectory of dementia, partly due to the difficulties with diagnosis and partly as a result of inadequate service provision and lack of agreement over the terminal course of the disease (WHO, 2012; van der Steen, 2009a, 2009b; Di Giulio, *et al.* 2008). ACP was introduced as a result of the GSF (DH, 2008), and is currently being promoted amongst all people with life limiting diseases, including dementia. However ACP for those who have advanced stages of the disease currently involves the input of family caregivers. ACP with family caregivers can provide an insight into what choices people with advanced dementia, who may be incapable of making informed decisions, may wish to make at the end of their life. Decisions such as artificial feeding, pain management and other active medical and nursing interventions are often discussed with family caregivers to achieve a consensus of opinion on how to act in the best interests of the patient.

The evaluation of a pilot study whereby the GSF was promoted in nursing homes for residents with dementia, in the north west of England (Ashton *et al.* 2009;

McClelland *et al* 2008), supported the expansion across other nursing homes across Greater Manchester and the north west region as part of the 'Six Steps Programme' (NHS NW EoLCP, 2011). It must be acknowledged that the study findings are dated and that there have since been developments in palliative care and ACP initiatives within nursing homes (DH, 2012, 2010). However the previous experience of the care setting staff is still relevant to this study as ACP initiatives and their impact on end of life care, involving much larger studies, have yet to be fully evaluated in the UK.

This thesis contributes to our understanding of the experience of ACP with family caregivers for the person with dementia at the end of life who resides in a nursing home. The purpose of this study is to contribute to the understanding of the experience of ACP by family caregivers, who often attempt to represent the person with dementia at the end of life.

5.2 Research Question and Study Objectives

This chapter has been organised in four main sections related to the original study objectives and reported under each separate study objective as a sub heading.

Research question

What are the experiences of family caregivers of undertaking ACP on behalf of people with advanced dementia?

Study Objectives

- To explore the psychosocial experience of family caregivers when caring for and/or supporting a person with advanced dementia, prior to and during admission within a long term care setting.

- To investigate the role of ACP in the care of people with dementia who are at the end of life from the perspectives of family caregivers within a long term care setting.

- To analyse the experience of family caregivers when undertaking ACP with professional care setting staff within the long term care environment, to inform future skill and knowledge development amongst health care professionals.

- To identify the essential knowledge and communication skills required by care professionals when facilitating ACP with family caregivers of people with advanced dementia that are at the end of life.

5.2.1 To explore the psychosocial experience of family caregivers when caring for and/or supporting a person with advanced dementia, prior to and during admission within a long term care setting.

The first study objective related to the previous 'dementia journey' that had been experienced by the family caregiver in relation to their caring role, from initial diagnosis to the admission to a long term care setting. The purpose was to identify any common concepts from each participant in relation to their experience of dementia which could have lasted for several years. It was also important to recognise the story of the person with dementia, as told by the family caregiver, to acknowledge that they were/are central to the research. This objective also provided an opportunity to examine the circumstances prior to the admission to long term care and examine the impact of this on the family caregiver experience.

5.2.1.1 The Dementia Journey

Dementia is a life limiting disease with an unpredictable disease trajectory (Mitchell, *et al.* 2004a, 2004b). The impact of diagnosis is not only distressing and life changing for the person diagnosed with dementia but it also has potential to impact upon the family. The interviews with family caregivers in this study suggested a collective vision regarding the difficulties with the diagnosis of dementia. A recurring theme in this study was the need for early diagnosis and adequate inter-professional co-operation and competence in dementia care. The difficulties with diagnosing dementia have been acknowledged (NAO, 2010; WHO, 2012) and were confirmed by family caregivers in this study by frustrated discussions with doctors which emerged as a common picture and a relief when a diagnosis was made, even one as potentially devastating as dementia. Relief of the diagnosis for other life limiting illness was also

found by O'Brien, *et al.* (2011b) following the diagnosis of Motor Neurone Disease, which suggested that putting a name to the symptoms was traumatic but also a release.

The family caregivers in this study were anticipating treatment and support as a result of the diagnosis but were disappointed with the level of support and guidance as the 'dementia journey' examples suggested. The WHO (2012) identified that following diagnosis the dementia sufferer is entitled to a multi-agency sustainable integrated programme of supportive structures to improve quality of life to enable the person to live in the community for as long as possible. In this study continual difficulties in accessing appropriate advice and support from health and social care professionals were common examples, and supported previous national and international evidence of the difficulties in diagnosis and lack of interest amongst politicians, physicians and researchers (WHO, 2012; DH, 2011a; DH, 2011b; NAO, 2007; Stieber-Roger, 2006; Innes, 2002; DH, 2001). In the UK only 43% of people with dementia have a diagnosis and this varies across the country (Alzheimer's Society, 2012). This lack of clarity of service provision and diagnostic delay were also cited in other studies within the UK involving life limiting disease, not just for dementia (O'Brien, *et al.* 2011a, O'Brien, *et al.* 2011b).

The consequences of a lack of structured interventions could have consequences for the early admission to long term care (WHO, 2012; Andren and Elmstahl, 2008). The family caregivers in this study reported that as the dementia progressed there was an emerging picture of mental and physical decline and the diagnosed person became more dependent for protection and general decision making. An All Party

Parliamentary Group on Dementia Report for the Alzheimer's Society (2012) confirmed that following diagnosis, people with dementia and their family caregivers receive no information or support and GPs often act as more of a barrier than a gatekeeper to services. Early knowledge of the diagnosis and associated features of dementia may facilitate timely counselling and provision of information to people with dementia and their caregivers (WHO, 2012; Roelands, 2005).

The practical, psychological and economic strain over several years as a consequence of their caring role has been well documented and several studies have also attempted to capture the psychological distress of the family caregiver of people with dementia (Albinson and Strang, 2003a; Aggarwal *et al.* 2003; Robinson, *et al.* 2005; Galvin, *et al.* 2005; Papastavrou, *et al.* 2007). As in this study the experience of the disease was shared by the sufferer and the family as they both experience the change in relationship between husband and wife, mother and son, and brother and sister as the person they once knew 'disappears'. 'Anticipatory grief' captures the experience of the family carers as they witness the gradual disappearance of the person they once knew as a result of the dementia. Lindstom, *et al.* (2011a) suggest that this 'anticipatory grief' can impact on bereavement and is often experienced at different stages of the disease from diagnosis to death. This was also confirmed in this study as family caregivers often attempted to reflect on positive previous experiences prior to the advanced stage of the dementia in an attempt to preserve the real meaning of their relationship with their relative.

5.2.1.2 Admission to Long Term Care

Dementia is a major reason why a person receives institutional care (CQC, 2010) and at least two thirds of people living in care homes have a form of dementia (NAO, 2007). Smith (2009) suggested that in the British health care system people with equally debilitating disease can be treated differently in terms of the care they receive. Poor diagnosis of dementia, early in the disease trajectory, contributes to inequity as people cannot access the specialist support they may need (WHO, 2012; DH, 2012, 2009).

There have been concerns over the quality within long term care within the United Kingdom and in particular the availability of specialist dementia care in all care homes (CQC, 2010). In this study, as the disease progressed, the family caregiver was ultimately often faced with the decision about their ability to meet the needs of their relative and if the need for long term care was a more suitable option. Despite the increasingly mental frailty of their relative, the decision to consider long term care was often the result of a crisis event. This was expressed during the interviews as a distressing emotional decision which was often accompanied by crying and outbursts of anger. The anger was directed at the lack of adequate support and practical guidance and also the frustration of feeling isolated with the burden of decision making when caring for a virtual stranger who at times presented with unpredictable behaviour and challenging care needs.

Family caregivers cited the negative experience of hospital care, prior to admission to the nursing home, received by the person with dementia. A lack of care, understanding and expert knowledge was cited as examples by the family caregivers

in this study. This has also been documented in various reports over several years that health professional's attitudes and knowledge can negatively impact upon the care received in secondary care (Alzheimer's Society, 2012; Parker and Froggatt, 2011; CQC, 2010; DH, 2009). Results from the literature suggest that educated and knowledgeable health professionals can have a positive impact upon how they assess, interpret and manage the needs of people with advanced dementia. whatever the care setting (Casey, *et al.* 2011; Ashton, *et al.* 2009 McClelland, *et al.* 2008; Roelands, 2005). Expectations of good care were not realised by the family caregivers during these crisis events. citing a lack of skills and knowledge or health professionals and occasional negative attitudes when caring for older people, and particularly those with dementia.

It was difficult to ascertain that if support services had been more forthcoming whether the admission to the nursing home could have been delayed or prevented. It appeared that nursing home admission was accepted reluctantly by family caregivers as inevitable as they tried to do the right thing to safeguard their relatives and prevent any further potential injury

5.2.1.3 Choosing a Nursing Home

The long term care of people in the UK is mainly delivered within the independent sector and therefore subject to certain financial and selective admission criteria (Dilnot, 2011; Ham, 2004; Innes, 2002). It is reported that 45% of care home places are occupied by people who are self financing rather than paid for by the state (CQC, 2011a). There were similarities amongst the family caregivers in their experiences prior to and following admission to long term care of their relative. The family

caregivers reported that they often found themselves in the difficult position of having to find suitable accommodation and became almost 'pseudo inspectors' of nursing homes as they looked for a suitable place in which to place their relative with advanced dementia. The CQC (2011b) offers a national resource and information on care homes. However the family caregivers did not mention the CQC or appear to have any specific knowledge of what to look for.

What family caregivers used as 'criteria' was often expressed as ranging from 'gut feelings' to seeking advice from lay people (friends, relatives) who had previously had a similar decision to make. Only one of the family caregivers suggested that a health professional made a recommendation of a specific nursing home which would be able to meet the needs of the person with dementia. This had the desired effect and was reported as being beneficial which idealised the health professional as a 'godsend', suggesting they were acting in addition to their role.

The family caregivers did express what their expectations were of a 'good nursing home'. Good practice was acknowledged by the family caregivers as the nursing home having friendly staff with good communication skills, clean environments, no offensive odours, and where possible, personal recommendations from friends and acquaintances. Family caregivers know what it is like to take care of someone with dementia but may be reluctant to transfer the decision making to the nursing home staff (Finnema, *et al.* 2001). Finnema, *et al.* (2001) suggest this is when the family caregiver changes from primary caregiver to visitor. It was unclear why limited advice was given by health and social care professionals as to what constitutes a good long term care environment or nursing home. A lack of a coordinated approach

between public/ private establishments may offer one reason why caregivers are not supported (WHO, 2012). Public sector health and social care professionals may also feel that it is a conflict of interest to recommend private nursing homes to family caregivers, although there is no evidence relating to this. Health professionals may feel that they also have insufficient knowledge and experience to provide expert information.

5.2.1.4 The Experience of the Nursing Home

Once their relative was admitted to the nursing home, the family caregiver remained anxious and concerned to ensure that they had their needs met and were cared for by kind and considerate people. This has been confirmed in other studies, suggesting family caregivers remain anxious about their relative's happiness and the deteriorating relationship (Aggarwal et al. 2003; Albinson and Strang, 2003a, 2003b) suggesting that health and social care professionals need to continue to support family caregivers in their experiences of the dementia journey, despite admission to a nursing home

Strong feelings were demonstrated (crying) and reported by family caregivers as being upset when the person no longer recognises them or mistakes them for someone else. Albinson and Strang's (2003a) study also described this lack of communication and dignity in the resident's life, suggesting it was like going to visit a dead person and that the family caregivers had begun grieving at a much earlier stage. None of the family caregivers in this study reported their relative as being like a dead person, however one participant expressed a desire for his wife to have suffered with cancer

rather than dementia in which he demonstrated strong feeling about the disease and the hopelessness he felt.

Albinson & Strang (2003a) suggested that allowing families to verbalise their existential thoughts and supporting them in their existential crisis could be of great importance to enable them to cope and adjust in the future. In this study family caregivers expressed similarities in their experiences of the care setting and often needed reassurance and access to opportunities to discuss their feelings relating to their experiences of dementia and visiting the care setting. Despite good intentions from care staff, nursing homes are community dwellings and within them reside people with varying degrees of physical and mental frailty. Standards of care in nursing homes vary depending on the residents' needs, staffing levels and knowledge and skills of the care staff (CQC, 2011a). Trust in the care setting staff to deliver appropriate care to their relatives was an important feature for all the family caregivers in this study. The personal involvement of the care setting staff in the resident's life and also their own lives was seen as an important feature of good practice in the nursing home. Active interventions and interest in family caregivers by care setting staff have also been demonstrated in other studies suggesting how this can provide insights into how to work with family caregivers to improve residents' care (Molyneaux, et al. 2011; Kellett, et al. 2010; Roelands, 2005). Good communication skills of care staff in caring professions has also been highlighted in previous studies as being essential, citing the need for specific training so health and social care professionals can understand and manage the feelings of family caregivers (Papastavrou, et al. 2007).

5.2.1.5 Summary

The diagnosis of dementia appears to be a combination of frustration and also relief. 'Relief' was expressed as a result of the frustration of diagnosis which suggested that improvements must be made to improve early diagnosis and interventions. The stress and anxiety of the dementia journey does not end, nor is it abdicated by the family caregiver despite the admission to long term care. Despite the positive caring experiences within the care setting some family caregivers did have reservations about the continuity of care at different times, and with different staff, suggesting a lack of continuity of care that they had witnessed, or as a result of previous experiences in other settings. Family caregivers continued to express responsibility and duty towards their relatives' experience despite being in long term care environments.

Residents with advanced dementia in nursing homes cannot be seen in isolation to their family caregivers. Staff must ensure that the family caregivers are given sufficient support and acknowledgement of the difficult journey they have also travelled, and that for them it has not ended with admission. Sensitivity and respect are essential factors for care setting staff to display with relatives, however challenging they may be as a result of their continued anxiety and distress.

5.2.2 To investigate the role of Advance Care Planning in the care of people with dementia who are at the end of life, from the perspectives of family caregivers within a long term care setting.

As stated in chapter two, the literature suggested that people with dementia are less likely to be referred to palliative care services, or if they were referred this was often late in the disease, indicating a lack of opportunity to participate in ACP (Houttekier, et al. 2010). The WHO (2012) suggest a supported decision making model should be introduced soon after the diagnosis of dementia. The model supports the involvement of the person with dementia as much as possible at every stage, from diagnosis to the advanced stage, so that when capacity is eventually impaired those supporting the person, including family caregivers, have a good understanding of their care preferences and wishes as they approach the end of their life and are in a better position to determine what the person would have wanted. This could include identifying and documenting individual future care preferences (ACP) and organising legal and financial arrangements (Smith, 2009) which otherwise may not be addressed until late into the disease, which is what appeared to have happened for the family caregivers in this study.

A problematic issue highlighted in the literature, was the lack of agreement when people with advanced dementia were dying or deteriorating (Di Giulio, et al. 2008; Mitchell, et al. 2007b). Prognostic indicator guidance can provide opportunities to increase awareness of when to initiate a palliative care approach (DH, 2010; Thomas, 2003). However despite the attempt to produce and make available clinical indicators there is evidence within the literature to suggest that these are not interpreted

consistently amongst health professionals (van der Steen 2010; Mitchell, *et al.* 2009). If dying from dementia is not recognised in the advanced stage of the disease then ACP discussions become 'last minute' and are therefore likely to cause distress and anxiety for family caregivers as they are asked to contribute to a decision for which they are not prepared (Di Giulio, *et al.* 2008; Formiga, *et al.* 2007). Due to the facilitation of ACP within the care setting identified in this study, family caregivers were introduced to the role of palliative care prior to the proximity of death, although it should be acknowledged that each resident was in an already advanced stage of the disease.

ACP is more common in the USA and Australia, but there remains difficulties in incorporating ACP for people with dementia (Yeung-Sim Jeong, *et al.* 2011; Lacy, 2006; Engel, *et al.* 2006). Despite ACP being well developed within the Netherlands it would appear that physicians still have influence over treatment decisions at the end of life (De Boer, *et al.* 2011; Rurup, *et al.* 2006). In the UK, ACP is a relatively new concept and has limited impact to date on end of life care in life limiting disease (Preston, 2011). The consequence of inadequate preparation for the deterioration of people with advanced dementia has the potential for adding to the suffering of the dying (Di Giulio, *et al.* 2008). However recent UK local and national initiatives for end of life care which relate to the GSF, and include ACP (DH, 2008, 2010) have been suggested to have the potential to improve end of life care (Shaw, *et al.* 2010) for all life limiting conditions. This second objective within this study explored the role of ACP in the care of people with dementia who are at the end of life from the perspectives of family caregivers within a long term care setting (nursing home). The findings suggested that family caregivers agreed that ACP had a role in preparing for

the inevitable end of life care for people with advanced dementia who were not able to contribute to, or make known, their own end of life care preferences.

5.2.2.1 Appropriateness of Advance Care Planning

There was general agreement from all family caregivers that ACP was appropriate for people with advanced dementia. The previous knowledge and experiences of family caregivers during the dementia journey offered a compelling argument that it was important for relatives to be involved in the end of life care discussions. The family caregivers had been supporting the person with dementia for several years and would naturally feel protective towards their wellbeing. Samsi and Manthorpe (2011) suggested that ACP was driven by individual disposition and so there is a need to identify the rationale, the benefits and support available to family caregivers to complete an ACP. WHO (2012) suggested that to avoid or reduce the problems associated with lack of capacity the role of trusted family caregivers or advocates must be given greater consideration throughout the dementia journey to support the preferences of the person with dementia. Earlier studies have suggested that when previous discussions have not taken place this can be problematic for relatives to represent their wishes (Elliot, et al. 2009; Black, et al. 2009).

Despite their obvious distress during their recollections of the ACP discussion, the family caregivers in this study welcomed the opportunity to be involved in end of life care decisions, and expressed this as their duty of care. Some identified previous discussions of end of life care and future care needs with their relatives but most of the family caregivers did not. The involvement in ACP allowed the family caregivers to have some control over the caring process and remove the disempowerment of

their caring role (Molyneaux, *et al.* 2011). Positive engagement and creating a person-centred approach promoted insights into the appreciation of how to work with family caregivers (Lindstrom *et al.* 2011a; Kellet, *et al.* 2010; Moorman and Carr, 2008).

ACP also provided an opportunity to discuss 'the essence of their being' which was not limited to medical care and treatments (Jeong, *et al.* 2012). Reviving memories of the whole person with dementia (Kellett, *et al.* 2010) was very important to family caregivers in this study. The opportunity to revive memories and share stories of their relative was a positive outcome of ACP discussions. The person with dementia was the focus of the ACP discussion which appeared to reassure the family caregiver that any future decisions were made with their best interests and with sensitivity.

5.2.2.2 Readiness to Discuss Advance Care Planning

Woods (2007) argued that professionals often make assumptions concerning the relationship with the dying person that may, or may not, be accurate, and this often represents another layer of complexity in the decision making within palliative care. In this study there appeared to be an assumption by care staff in the way the ACP was approached and that the family caregivers wanted to make these decisions and would welcome a role in determining a person's best interest at the end of life. However in other studies nursing staff have avoided or been reluctant to discuss ACP (Yeun-Sim Jeong, *et al.* 2011; Sampson, *et al.* 2008; Moss, *et al.* 2002b). The family caregivers suggested that ACP was an individual issue and should be commenced when the family member was ready to discuss it. Some needed time to reflect on the meaning of ACP and some chose to discuss it with other family members. Seeking out the

opinions or approval of other family members sometimes offered insights into what previous discussions had taken place. This was also confirmed by the staff in the care settings and supports the need for ACP discussions much earlier in the disease trajectory.

Family caregivers experience pre-death anticipatory grief for several years due to the psychosocial loss of the person with dementia. Lindstrom, et al. (2011a:260) suggested that by the time the person reaches the advanced stage of the disease 'grief intensity' is at its peak. Lindstrom et al. (2011a) suggested the use of the Marwit-Meuser Caregiver Grief Inventory (MM-CGI) (Meuser, et al. 2004) with family caregivers to assess the intensity and patterns of grief they feel and direct them to more effective ways of coping. There did not appear to be any assessments made before or after the completion of ACP documents by the care setting staff. However the ACP discussions appeared to give the family caregivers an opportunity to discharge their feelings; however a more formal assessment or discussion on the grief experience prior to the ACP may be appropriate to avoid further distress.

Other studies, both national and international, suggested that although ACP is considered to be favourable in identifying the needs of people as they enter the dying phase, it is often haphazard and subject to the individual preferences of health and social care professionals (Dwyer, et al. 2010; Yung, et al. 2010). In this study the residents admitted to the nursing home's specialist dementia unit had an advanced stage of the disease which is likely to have facilitated the ACP discussions, but there was still a need for the family caregiver to accept that their relative would deteriorate. The deviant case highlighted in chapter five identified the important issue of

'readiness'. Despite her husband's deteriorating condition due to dementia, this study participant was not ready to discuss this, or end of life issues, and this was confirmed by the lack of completion of the ACP in the nursing care notes. The family caregiver appeared to lack insight or was in denial about the diagnosis and prognosis and this appeared to interfere with the ACP discussions. Separation distress has been highlighted by Kiely, *et al.* (2008) as a common death grief symptom for family caregivers of people with dementia before their actual death, and sensitivity and support is needed to reduce distress.

The family caregivers did suggest that ACP discussions were facilitated in an empathetic and sensitive way. ACP discussions earlier in the disease would enable family caregivers to be more ready for contributing to decisions but more importantly would have a better understanding of what to expect. Interventions could include, education, behaviour management, communication, the disease trajectory and symptom management at the end of life (Kellett, *et al.* 2010; Wakunami, *et al.* 2009; Engel, *et al.* 2006).

Although cited as an uncomfortable process, family caregivers did accept that ACP assisted them to prepare for the death of their relative which prompted discussions on the treatment and care options. This is supported in some previous studies (Stewart, *et al.*2011; Yung, *et al.* 2010) but not in others as family caregivers lack engagement or have had disappointing experiences of ACP (Preston, *et al.* 2011; Sampson, *et al.* 2010). Previous studies suggest that care setting staff also need to be ready and be prepared to discuss ACP honestly with family caregivers (Goodwin and Waters, 2009; Yeun-Sim Jeong, *et al.* 2011).

5.2.2.3 Communication Skills

ACP is not commonplace in the UK (Royal College of Physicians (RCP), 2009) so it would appear that health professionals are reliant on the information provided by family caregivers and their own professional values and knowledge base. Trust in the care setting and feeling part of the care process was cited as being important by the family caregivers to facilitate ACP discussions. Consistency with care providers and the need to acknowledge the care relationship between family caregiver and the person with dementia has also been cited in other studies (Molyneaux, *et al.* 2011; Finnema, 2001; Forbes, *et al.* 2000).

A feature of the ACP opportunity for the family caregiver in this study was the need to clarify how their relative would deteriorate and what physical and mental symptoms would present due to a deteriorating body. A lack of communication between family caregiver and the resident was cited as distressing and contributed to their distress. Albinson and Strang (2003b) refer to this as devastating as the family caregiver witnesses the deterioration.

ACP had an advantage for the care setting staff to establish with the family caregiver their expectations and what they believe constitutes good practice. Elliot, *et al.* (2009) suggested that discussions in terms of best interests are meaningful to family caregivers. Best interests were cited by family caregivers in this study as those which caused the least distress and suffering. Best interests can be difficult to interpret by care setting staff so more than one ACP discussion was facilitated to establish a rapport and clarify meaning. It was important for family caregivers to share ideas and information during the ACP discussions and identify what support they could expect

from the setting. It also allowed them to confront important and inevitable decisions that had to be made as the resident deteriorated. which they may have previously avoided. A lack of communication with family caregivers can only contribute to misunderstandings, misconceptions and anxieties associated with the resident who is deteriorating. This has been expressed clearly by participants from the experience of sharing the dementia journey.

5.2.2.4 End of Life Care

ACP appeared to have a positive effect on the circumstances and care during the end of life of the residents. As reported by some family caregivers ACP provided a platform to discuss care at the end of life and to identify any potential conflict, with or between family members. prior to the deterioration of the resident. Family caregivers acknowledged the potential to influence the end of life care decisions. which included hospitalisation and artificial feeding. They reported that the care setting staff were sensitive to the needs of family caregivers. and how inappropriate interventions might be avoided. with full and honest discussions during ACP. ACP in this context therefore included an active intervention for family caregivers (Sampson. *et al.* 2008) as well as planning future care for the resident.

Family caregivers reported being prepared for the deterioration and death and that they felt included in the end of life care pathway. This engagement in the care process allowed family caregivers to contribute to the care setting rather than just be a visitor. which was also found in a previous study (Kellett. *et al.* 2010).

Five residents died during the study period. Generally all family caregivers were satisfied with the end of life care arrangements for their relatives and suggested that ACP contributed to their readiness and contribution to end of life care. During the ACP discussions, the family caregivers reported that they preferred their relative to die in the current care setting. This view is not uncommon in studies where family caregivers often have a preference for comfort care (Detering, *et al.* 2010; Engel, *et al.*2006; Lamberg, *et al.* 2005), providing they have been given an opportunity to be fully briefed on the disease trajectory and the potential symptom management at the end of life. This preference for comfort care is also dependent on the knowledge and skills of the health care professionals available to the family caregivers, as this has potential to overrule the family caregiver's preferences and the ACP (Detering, *et al.* 2010; Yung, *et al.* 2010; Yeun-Sim Jeong, *et al.* 2011; De Boer, *et al.* 2011).

Promoting communication between care setting staff and family caregivers appeared to avoid misunderstandings, misconceptions and anxieties associated with the resident who is deteriorating. Decisions were discussed in advance so as to avoid the 'last minute' decisions regarding artificial hydration and nutrition, treatment decisions for infectious diseases and use of analgesia.

However the finality of death was distressing for family caregivers following their intervention during the ACP and the end of life care pathway and unfortunately bereavement care appeared to be lacking. A consideration must be for health and social care professionals that the family caregiver has been part of the dementia journey for several years and now feels bereft not only for the loss of their relative but also the loss of a care-giving role. Goal 11 of the LCP focuses on providing

information of what to do next after a death. which should also include information on bereavement services and other appropriate agencies (Mula. 2011: Ellershaw and Wilkinson. 2011). ACP provided an opportunity to discuss funeral arrangements in advance of the resident's death and this was viewed as helpful by the family caregiver as it avoided the need to make difficult decisions immediately after death. Difficulties surrounding the death of the resident. either through suffering or medical interventions may compromise dignity and may contribute to feelings of not doing the right thing (Baldwin. 2006). In this study the family caregivers felt supported by the care staff and did not appear to have any unresolved guilt following the death of their relative. however this may not be replicated in other settings due to the concerns over staffing and standards in some nursing homes (COC. 2010. 2011a) and the potential for increased grief intensity should not be overlooked (Lindstrom. et al. 2011a).

5.2.2.5 Summary

ACP has a role in the care of people with dementia. regardless of the stage of the disease. The preferred approach as recommended by the WHO (2012) is a supported decision making model which involves the person with dementia as much as possible at every stage of the disease so that when capacity is eventually impaired. those supporting the person, including family caregivers, have a good understanding of their care preferences and wishes. However until improvements in the early diagnosis of dementia are available. the appropriate referral to health and social care services. and ACP is fully embedded in clinical practice with the person with dementia. it is likely that ACP will involve discussions with the family caregiver.

Discussing decisions in advance has the advantage of alerting the family caregiver to the potential difficulties experienced during the advanced stage of the disease. Preparation and assessment of their readiness to participate in ACP discussions is an important consideration and it should not be assumed that due to the severity of a disease that this would always be a welcome opportunity. Family caregivers in this study accepted that this was something they should be involved in so as to prepare for the inevitable deterioration of their relative, although this was not initially what they understood ACP to be. Their initial understanding of ACP was minimal until the care setting staff had explained the relevance and need.

Emerging issues that contributed to the need for ACP discussions, the implementation and the success of end of life care, were numerous and complex. Several important issues were identified and included, previous experience of hospital care, staff training and education in dementia, communication skills of health and social care professionals and the lack of time to adequately care and meet the needs of people with dementia. The role of the hospital for delivering palliative care to their relative was expressed in all cases as something that should be avoided and suggested previous experience of hospital care was influential in this opinion.

5.2.3 To analyse the experience of family caregivers when undertaking Advance Care Planning with professional care setting staff within the long term care environment, to inform future skill and knowledge development amongst health care professionals.

Forbes, *et al.* (2000:256) described the family members as travelling along a 'long, arduous and unwelcomed journey' but that death was not part of the day-to-day experience of the family members. Once admission to the nursing home had taken place the family caregivers in this study did not abdicate their roles or responsibilities of safeguarding their relative. This third objective was to analyse the experience of family caregivers when undertaking ACP with professional care setting staff within the long term care environment.

5.2.3.1 Facilitation of Advance Care Planning Discussions

ACP was the domain of the nursing staff within the nursing home setting in this study. Initially family caregivers expressed the view that they had some reservations about what ACP was. There was some suggestion by family caregivers that advanced dementia was viewed as a terminal condition and worthy of end of life discussions during the ACP process. However this was not always specified during the interviews. Terminal is often associated with cancer and not dementia, so terminology used by care professionals should be considered before ACP discussions. This acceptance to discuss end of life care has been cited in other studies where families attempt to act in the best interests of their relative (Elliott, *et al.* 2009; Wakunami, *et al.* 2009).

Having lived with the disease for several years, the family caregiver expressed little understanding of dementia and how this had manifested itself over time. Family-care home conflict is not uncommon due to confusion over the caring role when the resident is admitted to the nursing home (Kellett, *et al.* 2010; Aggarwal, *et al, 2003*). The family caregiver role changes from primary caregiver to a visitor (Finnema, 2001) following admission. It was important to the family caregiver that they were given an opportunity to contribute family knowledge and share the resident's history and their care experience. Kellett, *et al.* (2010) suggested that this opportunity empowers the family caregiver as they come to terms with their new role.

During ACP discussions some of the caregivers required a specific explanation of what would happen, why and when, which suggests a need for confidence in their decision making. Some suggested that they clarified what the ACP 'form' was about and some discussed it with their wider family to clarify whether or not they could make a decision about 'best interests'. This allowance by the senior nurse for open and honest discussions in some cases suggested an opportunity to seek alternative sources of information such as family, friends and the internet. The internet was a source for some family caregivers to access websites such as Age Concern (now Age UK) and the Alzheimer's Disease Society. This additional information empowered the family caregiver to seek out further clarification and opportunities with the care staff and senior nurse. This also allowed for amendments to the ACP, when armed with additional knowledge, to be facilitated in the 'staged' ACP management within the care setting.

The supportive role of the care setting staff in facilitating ACP discussions was essential to enable family caregivers to discuss sensitive subjects and clarify what medical interventions might be considered. Consideration and exploration of 'best interests' was the subject of other studies when engaging family caregivers in ACP discussions, in which the support from health professionals was also viewed as essential (Givens, *et al.* 2009; Black, *et al.* 2009; Elliot, *et al.* 2009). For the first time ACP provided an opportunity for the family caregiver to really explore the disease and its consequences with a knowledgeable professional. The intended outcome of ACP discussions should therefore be to develop confidence in the judgement of family caregivers to represent their relative's views on end of life care.

Conroy (2011a) suggests that high quality conversation skills and dedicated time are essential to allow ACP to take place. The family caregivers in this study suggested that the established relationship between them and the care setting staff was an important feature for allowing the discussion of sensitive subjects. A previous evaluation study suggested that as a result of the GSF intervention (Ashton, *et al.* 2009; DH, 2008; McClelland, *et al.* 2008) there was an emerging confidence amongst care setting staff to discuss issues of death and dying with family caregivers. Previous studies also suggest that if staff lack disease specific knowledge, confidence or feel uncomfortable, then ACP discussions are less likely to take place (Gott, *et al.* 2011; O'Brien, *et al.* 2011a; Yeun-Sim Jeong, *et al.* 2011; Goodman, *et al.* 2009; Mitchell, 2007a).

The inevitable decline of the resident with dementia will involve decisions regarding the clinical complications of advanced dementia, this includes, feeding problems,

infectious episodes, for example, pneumonia and pain (Givens, *et al.* 2009). In this study ACP discussions included information on the possible medical decisions that may be required by family caregivers. The care setting staff used the GSF 'Thinking Ahead' ACP form as a guide for these discussions (Appendix 9). Staff also had additional notes attached to the form to include personal preferences and details of review sessions that had taken place with family caregivers. Reviewing the ACP as the resident's condition changes was an important consideration for the care setting staff and family caregivers (Volicer, *et al.* 2002).

The importance of open and honest discussions cannot be underestimated to develop relationship of mutual respect and trust (Conroy, 2011a). Family caregivers did require specific information as they did not know in advance which questions to ask and how to ask them. In this study family caregivers were unprepared for swallowing difficulties and the role of artificial feeding, which only became a reality once the person had deteriorated. The reality of the decisions made by the family caregivers to represent their relative's wishes required additional support and reassurance by health professionals as their relative deteriorated. This support and reassurance was also confirmed by the care setting staff in other studies (Givens, *et al.* 2009; Elliot, *et al.* 2009) and confirms the need for review sessions once an ACP has been commenced. Allowing family caregivers to change their minds, include additional information following a health concern or illness or just to review current information is an important feature of an ACP (Conroy, 2011a). ACPs should not replace regular discussions between the family caregiver and members of the health care team and there should also be plans in place if the caregiver dies or also loses capacity so a new plan can be initiated (Volicer, *et al.* 2002).

Active interventions were cited by family caregivers as tube feeding, emergency procedures and hospitalisation, suggesting that the ACP discussions had included this specific information by the senior nurse. Other limited national and international studies have also suggested family caregivers' understanding of ACP includes: adequate pain control, attention to prior wishes, patient dying in desired location, and appropriate hospice referral and stress reduction for the caregiver (Casey, *et al.* 2011; Shega, *et al.* 2003).

In some of the responses from family caregivers, it was clear that previous experiences of care settings had an influence on the discussions and what was decided. Some concerns were expressed about how this 'plan' would be put into practice, particularly if the senior nurse was absent from the care setting. Variations in nursing staff and inconsistencies in care provision, either currently or previously in other care settings, appeared to contribute to some concerns from study family caregivers. Unfortunately these remain current issues within the independent sector in the UK and nursing homes in particular (CQC, 2011a). These issues have implications for ACP completion, as family caregivers suggest that trust in the care setting staff is vital for open and honest discussions.

5.2.3.2 Contributory Factors

It is important to acknowledged the emotional context in which family caregivers were involved in the admittance of their relative to a long term care setting but also the decision making process at the end of life for the person with advanced dementia. Chang and Schneider (2010) identified that it is not unusual for family caregivers to

demonstrate a strong grief response following nursing home placement and that health care providers rarely notice and so leave families to cope with their suffering.

Experiences of grief, loss, fear, anxiety, guilt and anger are often experienced by family caregivers of people with advanced dementia (Loboprabhu, et al. 2007). This may present as family caregivers being over anxious or critical of the care received and therefore they need to be given support and explanations in a timely and supported way by appropriately educated and experienced professionals. Care home staff needed to be empathetic to these feelings to enable family caregivers to cope with grief and loss which does not end with admission to nursing homes (Cairns, 2012; Chang and Schneider, 2010). It is important too that care staff acknowledge and accept the complex nature of family dynamics and the emotional context in which persons with dementia are admitted to long term care settings, and how this can impact upon relationships within the nursing home.

Family caregivers acknowledge the role of the senior nurse who was clearly identified as being instrumental in the avoidance of misunderstandings and changes of mind. The specialist dementia unit was a small unit of 18 beds, with a stable workforce. Although there is little known about the experience of family caregivers of residents with nursing staff, Verbeek, et al. (2012) suggest that small scale facilities and the personal attention that nursing staff provide is associated with family caregiver satisfaction.

The advanced stage of the disease was acknowledged as a contributing factor to completing an ACP, as family caregivers recognized the need to discuss end of life

care. The study from Wakunami, *et al.* (2009) identified that as the resident's condition deteriorated the family caregivers moved from a desire to prolong life to the acceptance of dying with dignity. The male respondents (sons and husband) were much more likely to express emotion in the form of crying than the female family caregivers during the interviews. During the debriefing session following the interviews the men were more likely to feel guilt and wanting to do, or wishing they could have done, more for their mother or wife. This unresolved guilt related to nursing home admission and the dementia itself expressing an injustice as to why this happened to them and their relative.

The feelings of inadequacy or helplessness by the family caregivers should be acknowledged by health and social care professionals if undertaking ACP or any discussions relating to the care of the person with dementia. Family caregivers need to be aware that emotional distress is to be expected, however health and social care professionals should be alert to excessive psychological distress which is not part of normal bereavement (Bergman, *et al.* 2011) and should have information about any available services.

5.2.3.4 Suffering

The majority of family caregivers did express an acceptance of the need to discuss end of life care. Chang and Schneider (2010) suggested that decisions on health care interventions are not made in isolation by the family caregivers but also include the consequences for themselves and their own families. There was an anticipation of suffering which did contribute to the willingness to engage with ACP. The

experience of the slow deterioration and severe mental frailty contributed to this resignation. However this resignation was not expressed as a need to hasten death but to ensure all comfort care was available when it was needed however long in the future this may be. 'Suffering' as identified by family caregivers in this study, was described as a lack of engagement and interaction, nonexistent communication, being bedridden and the indignity of being totally dependent on staff in the nursing home.

Confirmation of dying would therefore need to be explicitly explained to the family caregivers despite the completion of the ACP. The exception to this was that one daughter expressed a desire for her mother's condition to end and that she had 'suffered enough'. She expressed support for euthanasia and a need to end the suffering of her mother, representing the distress and anxiety that she felt and which reflects her experience of the dementia journey with her mother. Intimate contact with death, dying and suffering can evoke fear about mortality, and so family caregivers may resort to demonstrating signs of unbearable feelings or anxiety (Loboprabhu, et al. 2007; Woods, 2007; Sandman, 2005). Meller and Caplan (2009) suggest that ACP can provide a conduit between acute and palliative care by focusing on current and anticipated clinical need within a supported legal context whereby family and clinicians can act in the best interest of the resident.

An interpretation of suffering is subjective to the person witnessing it and it is difficult to know how much the anticipation of 'suffering' should be discussed in advance with family caregivers, for example, the likelihood of swallowing problems, breathing difficulties and agitation.

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5.2.3.5 Spiritual Care

Murray (2011) states that death is a four dimensional activity and includes; physical, social, psychological and spiritual. Spiritual care has a reputation of not being routinely discussed by nurses and other health professionals in cancer services as well as dementia care (MCCN, 2006; Mast, 2004; NICE, 2004). However new guidance suggests that care professionals need to give spiritual care much more attention at the end of life for all people (DH, 2010). DeMond (2010) identified the spiritual distress that family caregivers suffer as well as the physical and emotional distress.

An ACP may include an expression of religious or spiritual activity and ideally include instructions by the person before capacity is lost. ACP provides an opportunity for reflection not just for the future but also on the past (Watson, 2011). For those who have lost capacity it is left to those who were closest to the person to try and represent their wishes. ACP can trigger deep emotions as they associate the past with the present (Dinning, 2006). ACP includes important discussions that will live on in the memory of the bereaved as they try to do the right thing (Watson, 2011).

All family caregivers in this study referred to the 'loss of the person' with advanced dementia, whilst they were still alive. Loboprabhu, et al. (2007) identified the central issue of separation and loss in dementia which is accompanied by a gradual and painful separation from loved ones. Separation distress, referred to by Kiely, et al. (2008) was the most common pre-death symptom. It was clear during the interviews that the grief was still being experienced and the regret for a life lost and experiences missed by both. This was particularly prevalent in the interviews with the spouse.

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Lloyd, et al. (2011) suggested that it is often difficult to determine when a person is living with a disease (dementia) or dying from it. ACP provides a new reality for family caregivers in which they come to terms with the fact that death will happen. Planning for death has the potential to reduce its impact and control (Watson, 2011) and transforms the family caregiver to an active participant in the care process (Finnema, 2001).

Family caregivers often referred to personal themes when discussing the care during the dying phase or to justify the ACP discussions as they try to represent what their relative might have preferred. It was important to the family caregivers to discuss the person with dementia in a more individualised and less pathological way (Kellett, et al. 2010). Kellett, et al. (2010) suggested that such engagement promotes insight into and appreciation of how to work with families and improve resident care.

Personal themes related to what their relative's previous likes and dislikes were and what personality traits and interests they had prior to the advanced stage of the disease. Jeong, et al.'s, (2012) study supports the inclusion of personal themes in ACP and refers to this as the 'essence of being'. Murray (2011:259) suggests that spiritual needs can be defined as issues relating to meaning and purpose and may not be expressed using religious language'. Although none of the family caregivers initiated a spontaneous discussion about the meaning of religion in end of life care, some included the personal preferences in respect to religion and religious practices. Other personal themes included the use of music, flowers, privacy and who was to be in attendance to support the resident as they died. Funeral preparations were also discussed but this only appeared to be initiated when their relative was close to death

or if the relative spontaneously wanted it to be documented in the ACP. This is not uncommon in the UK and has prompted a national campaign (dying matters) to encourage people of all ages to have a more open and honest discussion with their friends and families about discussing preferences for funeral arrangements (NCPC, 2012).

Person-centred care remains appropriate to the person with advanced dementia. Kitwood, (1997) identified the main psychological needs of people with dementia – attachment, comfort, identity, occupation and inclusion which are all relevant to ACP discussions with family caregivers and the palliative care approach (Hughes, *et al.* 2006) as they tried to represent their relative in the context of their life history. It was difficult to ascertain who initiated the personal/person-centred themes during the ACP discussions but it was clear that these were very important as they planned for end of life care. Kellett (2010) suggested that family biographical information, if appropriate, should be integrated into the ongoing care of dementia residents and not be perceived as an additional outcome orientated task.

5.2.3.6 Summary

Family caregivers acknowledged the need to discuss end of life care issues with reluctance and regret in having to cope with this. A planned, occasionally informal and staged process, lasting over several weeks in some cases appeared to be an acceptable method to the family caregivers of facilitating the ACP. This staged process appeared to be related to the lack of information and understanding of the disease trajectory of dementia. It would be important to make sure that the family

caregiver was not overloaded with information too soon which may add to their distress and anxiety. The value of the ACP discussions with regard to opportunities to discuss the resident and their history, prepare for the inevitable end of life care, and discuss treatment options and interventions as the disease progresses were identified as being important to the family caregivers. Distress and discomfort during discussions and decision making were commonplace amongst the family caregivers as they struggled to make the right decisions with or without other family members' input. The trust in the care staff allowed for the ACP discussions to be facilitated within the care setting and it also allowed for family caregivers to have open and honest discussions. Trust was an essential factor for family caregivers if ACP was to take place.

5.2.4 To identify the essential knowledge and communication skills required by care professionals when facilitating Advance Care Planning with family caregivers of people with advanced dementia that are at the end of life.

Discussing death and dying with family caregivers is a stressful activity for any health professional. The need to be sensitive yet realistic is a combination that requires skill and experience in order to do it effectively (DH, 2010; DH, 2007). ACP discussions can be distressing especially if the health and social care professional does not have appropriate training or interpersonal skills (DH, 2010; RCP, 2009). ACP allows for discussion on sensitive topics but the health and social care professional needs to know how to ask the right questions and be prepared to educate the family caregiver on what to expect (Yeun-Sim Jeong, *et al.* 2011; Detering, *et al.* 2010). In this part of the chapter the final objective will establish the essential knowledge and communication skills required by care professionals when facilitating ACP with

family caregivers of people with advanced dementia who are at the end of life, regardless of the care setting.

5.2.4.1 The Needs of Patients, Residents and Family Caregivers

The lack of knowledge, skills and understanding of the disease trajectory of dementia has been of concern both nationally and internationally and as a consequence end of life care is open to burdensome and aggressive treatments described as being of 'questionable benefit' (Mitchell, et al. 2009). Previous studies suggest that poor communication and professional hierarchies contribute to a lack of discussion and earlier transition towards a palliative approach during the later stages of the disease in advanced dementia (Gott, et al. 2011; Goodwin and Waters, 2009).

The supported decision making model as recommended by the WHO (2012) commenced shortly after diagnosis, would involve the person with dementia as much as possible at every stage of their disease. As capacity is lost the person's preferences and wishes would have been documented over a period of time and known by a trusted family caregiver or advocate. If aggressive and other questionable interventions are to be avoided then there is a need to prepare in advance for the deterioration of terminal diseases such as dementia. Holman, et al. (2011:146) suggest that in order for ACP (GSF) to be embedded into everyday practice in care homes there needs to be an 'improvement in communication skills, improved collaborative working and a need to reconsider their documentation process'.

Education and training may reassure health professionals and change the attitudes towards the early recognition and avoidance for potential suffering for people with

dementia. The Department of Health (2009b) has identified common core competencies and principles for health and social care workers with adults at the end of life. Communication is a core clinical competency. These competencies set out expectations and skills which are appropriate for different levels of health care practitioners. Health and social care professionals also need guidance and frequent discussions with each other to generate skills and confidence to promote such end of life care discussions with patients and family caregivers. When multidisciplinary teams are involved in the development of guidelines, which are then implemented, there is potential for partnerships in care and the development of a collaborative approach to palliative care for patients with dementia (Lloyd-Williams and Payne, 2002). This also would provide reassurance and a consistent approach to anticipating the needs of people with advanced dementia.

Satisfaction with the current nursing home was indicated in this study by all the family caregivers (with the exception of the deviant case) by the communication skills and knowledge of care staff, the continuity of care from a stable workforce and the trust in care setting staff to treat their relative as an individual. In the early stages of the disease the patient and family caregivers in this study, were not sufficiently educated about the disease progression. This was compounded by a lack of a coordinated approach by all health and social care professionals and a lack of referral to specialist services and personnel early in the disease trajectory. The crisis events that led to admission to long term care often resulted in a need to find suitable accommodation that was not always planned for. Planning a relative's admission to a care home can result in a multitude of feelings such as ashamed, guilty, sorrowful and frustrated (Chang and Schneider, 2010). A lack of support and guidance by social

services on what constitutes suitable nursing home accommodation for someone with dementia was indicated by family caregivers as being particularly stressful. Advice from Age UK (2011), offer guidance on finding a nursing home which may indicate that family caregivers may not routinely receive appropriate advice and support from health and social care agencies and the local authority.

5.2.4.2 The Challenges of Advance Care Planning

ACP can have an impact on the reduction in hospitalisation and in the use of specific medical interventions (Herbert, *et al.* 2006; Froggatt and Payne, 2006; Watson, *et al.* 2006; Gandy, *et al.* 2010).

Therefore effective communication was highlighted to be a central issue for successful ACP discussions with the family caregivers of people with advanced dementia. Adequate assessment on admission to the nursing home should include a full and detailed discussion of the family history and the development of the disease. Family caregivers should be encouraged, as much as they wish to, to take a full and active part in the care of their relative with dementia and feel confident to ask questions and share decision making. Care setting staff should be knowledgeable about the disease trajectory and should have received adequate training and education in meeting the ongoing and palliative care needs of this group.

5.2.4.3 Composite Case Advance Care Planning Discussions in Long Term Care Settings

ACP is a complex activity to undertake with family caregivers of residents with advanced dementia in nursing homes. The composite case presented here has attempted to go beyond the descriptive data and attach significance to what was found so as to make sense of the findings and consider the meaning and implications for practice (Patton, 2002). Patton (2002) suggests that qualitative inquiry involves presenting a holistic picture of what the study is trying to portray.

The emerging topics which relate to ACP discussions are presented. This includes, the past/previous experience of the family caregiver which may influence ACP discussions, the role of the family caregiver within the nursing home, the satisfaction of family caregivers in the care of their relative within the nursing home and the management and completion of the ACP document between the family caregivers and the care setting staff.

Statements such as those in Table 5.1 do not fully represent the complexities of the family caregiver experience; however it does give an impression of cause and effect of successful ACP completion. Adequate education for both family caregivers and care setting staff would appear to be an essential component to promote structured and detailed discussions in ACP. Understanding of dementia and honest and open communications promoted a foundation of trust, sharing responsibilities and mutual respect between family caregivers and care setting staff in their role in the care of the resident in the nursing home.

Table 5.1 Composite Case for the Management of Advance Care Planning Discussions with Family Caregivers

Influences on ACP discussions and completion	ACP with family caregivers: what went well?	ACP with family caregivers: what did not go well?
Family caregivers previous experience of the dementia journey prior to admission to the Nursing Home	Family caregivers were given the opportunity to discuss their dementia journey and identify gaps in knowledge and understanding and express grief and anxieties.	Family caregivers had unresolved grief which did not always appear to be acknowledged by care setting staff.
The role of the family caregiver within the nursing home.	Family caregivers were given the opportunity to be part of the care planning within the nursing home.	Lack of knowledge and understanding of the disease trajectory caused anxieties amongst family caregivers.
Family caregiver's knowledge of the disease trajectory of dementia.	ACP provided a platform to confront an understanding of end of life care that may be required.	Family caregivers expressed concern that a lack of knowledge did not always prompt them to ask the right questions during ACP.
Satisfaction of the family caregiver in the care of their relative in the nursing home.	Trust was viewed as an essential issue for family caregivers. Also staff should demonstrate compassion, empathy, deliver person-centred care and be, knowledgeable in dementia.	Family caregivers had some reservations about the continuity of care at the end of life. Previous experiences of different care settings may influence discussions.
The management of ACP discussions and the readiness of family caregivers to undertake ACP.	Family caregivers expressed a need for several sessions followed by review of the ACP to ensure a good understanding and readiness for ACP discussions.	The deviant case demonstrated denial and a lack of understanding of the dementia journey.
The agreed goals of care with family caregivers prior to and during end of life care.	Family caregivers were given the opportunity to identify goals of care that included non medical interventions and well as symptom management.	The deviant case was reluctant to accept the diagnosis of dementia.
Ongoing care and after care, the identification of counselling and/or bereavement care for family caregivers.	Family caregiver involvement in the end of life care pathways, including LCP, was beneficial.	Family caregivers needed information and/ or opportunities to be supported in their own grief and bereavement at different stages of the dementia journey.

5.3 Limitations of the Research

The limitations of this study are outlined using the critical appraisal tool Critical Appraisal Skills Programme (CASP) (Public Health Resource Unit, 2006). There are a number of methodological limitations to the study which involved ACP with family caregivers and these are now discussed.

5.3.1 Advance Care Planning with Family Caregivers

The aim of this part of the study was to gain an understanding of the experiences of family caregivers when being asked to participate in ACP for people with advanced dementia. The study objectives were chosen to represent the experiences of family caregivers and what influenced their discussions with nursing home staff in respect of ACP. One study site was chosen, a specialist dementia unit within a large independent nursing home, registered with the CQC to meet the needs of frail, elderly residents with physical and mental health needs for people in an advanced stage of dementia. The study was designed to be a small scale qualitative study due to financial and other resource implications. The care setting had implemented a strategy of ACP with the family caregivers, which was not typical of nursing homes within the UK at the time of data collection.

There are limitations to conducting research within the context of one specialist dementia unit and with a small sample population. According to Evans and Goodman (2009) the intrinsic heterogeneity of nursing homes makes identifying representative care homes problematic.

Twelve participants agreed to be interviewed and all had been involved in completing an ACP. Four other family caregivers chose not to be included in the study and this was discussed with the home manager. Recent bereavement was one reason given and it would have been unethical to harass these family caregivers. However it cannot be said with any certainty why these family caregivers chose not to be involved and they could have been followed up at a later date. The purpose would be to add to existing research and inform future research on when and how to approach bereaved relatives.

The extent to which twelve respondents can be sufficient to represent other family caregivers in the UK who may experience similar circumstances is a limitation. The sample population were all white British and therefore did not represent the diversity of the current UK population. Cultural and religious diversity was not represented in the sample. Further studies would need to address this ethnic bias and include a more representative sample. The influence of the senior nurse who facilitated the ACP with the family caregivers and the level of education and training she had undertaken may also have explained the successful completion of the documents and could be explored further.

The purpose of using semi structured interviews was to gain an understanding of the experience of ACP from the perspective of family caregivers. Interviews were an appropriate data collection tool but using just one interview with each participant was restrictive and did not allow for any follow-up questions after the interviewee had time to reflect and consider their own responses. Interview data collected from family caregivers may possibly include distorted responses due to personal anxieties

and anger and also affected by the emotional state of the interviewee at the time of the interview (Patton, 2002). A second or third follow up interview may have yielded a richness of data, which could have explored how the family caregiver interpreted how the ACP was utilised by care setting staff as the resident deteriorated, and if the ACP contributed to their interpretation of a good death (Murray, *et al.* 2007). The extent to which the interviewees would have agreed to a follow-up interview was not known. If resources allowed it might also have been an opportunity to discuss with other family members their impressions and interpretations of ACP as a result of snowballing sampling.

The data collected during the interviews with family caregivers was often interrupted as a result of emotional outbursts or the need to recall aspects of their relative's life and history. The benefits of a semi structured interview is that it does allow for the participant to discuss issues which they feel are important but which the researcher needs to interpret as relevant (Yin, 2009). Allowing the participants adequate time to open up and feel comfortable was important and did allow for a temporary relationship to develop (Hermanns, 2004).

Using a variety of other methods such as observation, after death analysis documentation survey, further interviews with other professionals may have also added to the confirmation that the ACP was interpreted, administered and supported by all health and social care professionals within the nursing home. Patton (2002) suggests that using a mixed methods approach can build on the strengths of each type of data collection while minimising the weaknesses of any single approach. This would have allowed cross referencing to take place between documents, including

care plans and the ACP, to identify if the input from family caregivers was influential in a consistent approach by the care settings staff and other professionals involved in the resident's care.

Once transcribed, the interviews were subject to content analysis, and each transcript was peer reviewed by the supervision team. Examination and comparison of each interview transcript was undertaken. The sensitive and emotional content of the interviews was acknowledged and had the potential for researcher bias so this was balanced with an openness to discover meaning and differing interpretations. The one deviant case allowed for an alternative explanation and is important to acknowledge in a small scale study, as this deviant case may be the dominant representative in other care settings.

Despite the limitations this research does have potential to be useful so that others can evaluate the extent to which the results are applicable to other contexts and settings and diverse populations (Polit and Beck, 2008). Care staff who are engaged in generalist settings should be able to identify the experience of the family caregivers who are often solicited to make or contribute to difficult decisions about end of life care for their relative (with or without dementia) and identify the opportunities to engage with ACP at a much earlier stage. It would also identify how to avoid potential conflict with family caregivers by appreciating the difficult experience and role conflict they have once their relative is admitted to long term care.

5.4 Reflections on the Research Study

5.4.1 Introduction

As previously outlined in chapter four, qualitative interviewing was chosen for this study. Qualitative interviewing by its very nature involves a relationship with the study participant. Maxwell (2012) suggests that the researcher is the instrument and this plays a major role in the conduct of a qualitative study. An interview which involves sensitive topics requires careful planning in advance, especially if it is anticipated that the participant may become distressed (Rubin and Rubin, 1995). The interviewer must be empathetic to the distress of the participant but also remember that they are the researcher and not a counsellor (Hennink, *et al.* 2011). This part of the chapter explores my own personal journey and reflection on undertaking semi structured interviews on sensitive topics with potentially vulnerable people. Hewitt (2007:1156) suggests that *'reflection is not only to conduct a cognitive post-mortem, but also to look to the future through the practice of anticipation.'*

5.4.2 The Interview

Participants were invited initially by letter to participate in a research study relating to end of life care for people with advanced dementia who resided in a nursing home. Clarity was important so that anyone wishing to respond would know what the research was about and therefore could make an informed choice. I had some initial reservations about sending the letter, as I was acutely aware that some of the sample population had experienced a recent bereavement. Feedback from my supervisors and the matron from the nursing home provided me with some reassurance on the wording of the letter and the potential that any undue stress may be caused.

Participants who responded to the invitation, were given the opportunity to identify a mutually convenient time and place of their choosing to maximise comfort and put them at their ease. I felt sufficiently prepared to conduct the interviews and felt I was aware of my ethical responsibilities not to cause unnecessary upset and distress. As a registered nurse I believed myself to be experienced in dealing with bereaved and distressed people. However I was also aware that I was not there to be a nurse but a researcher. Murray (2003) suggests that the nurse researcher should not be confused with the nurse therapist and maintaining a clear boundary is essential. Data collection should be unbiased and should not lead participants into the answers that you, as researcher, would prefer, acting as a nurse therapist may have influence on the results.

I was invited into the participant's homes and made to feel welcome. It was essential to develop a rapport as quickly as possible as an interview, however short lived, is a personal relationship for a brief time as people trust you with their innermost thoughts and feelings. Skene (2007) suggested that initial contact can be problematic when the interview is focused on bereavement. Reinforcing the purpose of the study, consent forms and confidentiality all provided an opening conversation prior to the interview. A palm sized digital tape recorder was fairly discreet and most participants gave it no particular attention after the first few minutes. DeMarrais and Tisdale (2002) identify the importance of creating an emotional space where the participant can relive the difficult emotion and is dependent on the structure, and intimacy generated during the interviews. I admit I was surprised at how ready the study subjects were willing to talk to a complete stranger about the preparations they had made, either for the deterioration of their relative or for one who had recently died in the care setting.

My approach was similar to what Valentine (2007:170) refers to as *'empathetic distance'*. Listening, observing, taking notes and recording the interviews enabled me to engage with the interviewee without becoming too involved. I was careful not to interrupt and break silences that provided opportunities for the participants to reflect briefly and compose themselves where necessary. Valentine (2007) also suggested that listening carefully and responding confirms that the researcher is hearing and receiving what is being said.

The strong emotions displayed included; frustration, anxiety, anger, sadness, grief, disappointment and a sense of overwhelming loss. It was difficult not to be moved by such sadness and regret of the loss of a life they thought their relative could or should have had. I acknowledged their distress through supportive body language, eye contact and communicating an empathetic willingness to listen (Rubin and Rubin, 1995). I offered time out to pause their story, but this was always refused. When the participant became angry, often over a feeling of frustration or injustice, it was important that I remained calm but acknowledged their strong feelings and did not allow them to pursue their own agenda and vent their frustration. This was particularly challenging in the case identified as 'deviant'. This participant had many unresolved issues that centred about her unwillingness to accept that her husband had dementia, despite being a resident in a specialist dementia unit. It would have been very easy to interfere with this as a nurse therapist and I found it particularly difficult to keep an 'empathetic distance'.

5.4.3 Ethical Dimensions

The conflict for the researcher is two-fold, the need to minimise risk and the need to get results. Valentine (2007) suggests that ethical guidelines provide useful starting points but that preparation for interviews for sensitive topics needs much more careful planning.

During the interview some participants became very upset and cried and despite my offer to postpone or take a short break they had an urgency to tell me their story. It was essential I demonstrated the correct amount of interest and concern through appropriate body language and tone of voice. I had a goal to get information, but I also needed to be empathetic to support the family caregivers during their disclosures. Participant's welfare must always take priority over the research (Walls, *et al.* 2010) and it was important that I had fully considered the need to build in an offer of referral if needed. Only one participant asked for more information on the availability of counselling services and how to approach his GP, as he expressed some surprise at his crying during the interview. I obtained the appropriate information and posted this, suggesting he take this to his GP. I also gave him my details should he require any further information or advice.

Legard, *et al.* (2003) suggests that the researcher needs to be constantly receptive to the body language and tone of voice of the participant. The researcher can anticipate in advance the likelihood of an emotional response from the participant and can therefore prepare for this. Rubin and Rubin (1995) suggest it is not for the researcher, but the participant to decide if they want to continue with an interview if they become distressed. There is the need to convey to the participants that it is all right to get

upset (Valentine, 2007) but that the researcher is not a trained counsellor and this should be clearly understood (Hennink, *et al.* 2011; Hallowell, *et al.* 2005).

I allowed time after the interview for feedback and discussion but I did not meet the study participants at any other time. In part I was relieved when the interview was over; it was not just emotionally draining for them it also was for me. Following the interview it was important to remain, in order to give time for the interviewee to compose themselves and provide an opportunity to retract any information. This was often much easier than I thought it would be. There was a sense of relief from the participants that they felt better that they had told their story, and hoped it would do some good for others. Walls, *et al.* (2010) suggest that participants often experience qualitative interviews as cathartic and therapeutic and Valentine (2007) states that it may provide relief and reinforcement of their (participants') experiences, choosing only to disclose as much as they wish. There was value in undertaking the interviews with family caregivers as they expressed appreciation at being able to discuss their experiences. However, Valentine (2007) also states that this cannot be generalised as it is difficult to predict how someone will act.

5.4.4 Data Analysis

Walls, *et al.* (2010) reported that research that intrudes into private spheres can be potentially distressing and emotive for the researcher. However it was only later when I came to transcribe the interviews that I realised how affected I had been by the respondent's experience. I had not fully addressed my own feelings after the interview had been concluded. On reflection I now feel that I had an unrealistic expectation of my ability to deal with emotional encounters because I was a registered

nurse and had done this countless times during my career. Debriefing is considered by deMarrais and Tisdale (2002) as being important especially if researching alone, as I was.

During the transcription of the interviews my own father was diagnosed with terminal cancer and died a few months later. I was immersed with death, dying and my own and my father's grief as he came to terms with his own death. My experience of interviewing those relatives gave me insight into the need to talk and discuss sensitive issues and allowed me a brief moment to talk, instigated by my father about what he might want as his disease progressed.

I was unable to recommence the transcription for several months following my father's death and even then I found it very difficult. My supervisors were very supportive and offered advice as to how I could deal with these emotions. However I still felt that this was something I should have been able to do as a registered nurse. Valentine (2007) describes this as the 'emotional pain of research' suggesting that the researcher must plan strategies for dealing with our own emotional distress (DeMarrais and Tisdale, 2002) which includes planning how the researcher will recover from the intensity of the encounter. This role blurring has implications for all nurse researchers who undertake qualitative interviews. Rouslton, et al. (2003) suggests that those who teach interview skills might assist researchers to develop skills and therefore make a clear distinction between the two roles.

My supervisors understood my own 'pain' and my emotional response, both being experienced in this type of research. They gave me an opportunity to talk but I found

it difficult to articulate my own grief. This emotional response has made me acutely aware of the need to report the findings in an unbiased way. I intended to send a copy of all transcribed interviews to the participants for 'member checking' (Skene, 2007) for accuracy, however due to the delay in transcription as a result of my own bereavement I considered the ethical issues of revisiting their discussions when they may have moved on. I was also mindful that some of the participant's relatives may have died or be dying and may not welcome this intrusion. The participants had all my details and had not contacted me since. I have therefore relied on my own integrity in the accurate transcription of the interviews and the peer review of the interview transcripts during analysis by my supervision team.

5.4.5 Summary and Implications for Qualitative Interviewers

When discussing care at the end of life, the researcher has to accept that some participants involved in this type of study may become distressed or emotional depending on their previous experiences both personally and professionally. Empathy, according to Patton (1990) develops from personal contact with the people being interviewed and involves being able to take and understand the position, feelings, experiences and world view of others. Empathy communicates interest and a care about people (Patton, 1990, 2002) however in qualitative research, for the findings to be credible, there needs to be a balance between empathy and neutrality. Patton (1990) argues that neutrality can facilitate rapport and help build a relationship that supports empathy through the non-judgemental approach by the researcher. Study participants should feel supported in their discussions but also feel comfortable to contribute honestly during data collection.

Hewitt (2007:1156) suggests that if nurse researchers are to fully address 'the moral complexities of the research relationships' then they need to be 'sensitive to the needs of participants from conception of the research to the reporting of findings'. Ethical guidelines and professional bodies can be useful sources of advice and guidance when planning research on sensitive subjects (NMC, 2008; RCN, 2009; NPSA/NRES, 2010). However support should also be available to the researcher to encourage them to discuss their own feelings and experiences on interviewing sensitive subjects and share this for the benefit of others.

5.5 Implications for Policy, Practice and Research

5.5.1 Implications for Policy

The lack of attention to the needs of people with dementia and their family caregivers has been highlighted for several years within the UK and in more recent times the urgency is gaining momentum (Alzheimer's Society, 2012; DH, 2009). With the anticipated numbers of people with dementia, not just in the UK but globally, there is a need for an appreciation of the role of palliative care approach earlier in the disease trajectory (WHO, 2012; NAO, 2007; NICE, 2006). ACP, in conjunction with active treatment, rehabilitation and palliative care should be part of the care strategy from diagnosis, eventually superseding the need for intervention and treatments as the person enters the terminal stage of the disease (DH, 2009a).

Family caregivers in this study were asked if they could suggest improvements in health and social care services for people with dementia and their relatives and carers. The family caregivers suggested recommendations for improvements, which they

based on their previous and current experiences of the dementia journey. These suggestions from family caregivers have implications for policy, as according to their experience, current health and social care arrangements do not adequately address the needs of people with dementia or their family caregivers.

A recurring theme was the need for early diagnosis and adequate inter-professional cooperation to ensure a streamlined early service referral to appropriate specialist providers, which should include palliative care. Despite attention to dementia over the last few years there remains concerns that some of these issues are not being dealt with, with any urgency (Alzheimer's Society, 2012). Referral to a range of support services for advice and support was also reported as important for monitoring and selecting treatment and care options. The range of support services should include public, private and voluntary services so that choices can be made to best suit the person and their caregivers depending on the stage of their disease. Family caregivers also expressed an urgent need, often expressed intensely, to educate and train the family caregivers and people with a diagnosis of dementia in the practical skills and behaviour management techniques to ensure they are adequately prepared for the disease as it progresses (DH, 2011a; DH, 2009a). Currently this is problematic due to the difficulties in the delay in early diagnosis and also a lack of a coordinated approach and lack of education and training for generalist (non mental health) health and social care professionals and care workers. Early interventions for people with dementia and their families may delay/prevent admission to long term care which could be of social and economic benefit.

The independent sector is a major provider of care for older people and people with dementia (CQC, 2010). The National End of Life Care Strategy for people with chronic illness, including dementia, is that this should be provided in the care setting of their choice and delivered by educated generalist staff supported by palliative care professionals (DH, 2008). ACP discussions should take place shortly after diagnosis to ensure the person remains fully in control of their care for as long as possible. ACP should be central to the coordinated approach to diagnosis and service provision as suggested by the WHO (2012). The Dementia Voice Nurse (DVN) Service Pilot recently published its report in March 2012 and initial findings suggest that providing a key professional as a central source of support and information has been beneficial to both the patient with dementia and family caregivers (Research and Evaluation Team Housing 21, 2012). At the end of the pilot 84% (n=20) of people with dementia had died in their preferred place of death. Barriers to the DVN service included gaps in GP knowledge, inter-professional scepticism and a lack of shared information.

It is essential to acknowledge and provide adequate resources to enhance the education and training of all care setting staff, pre-registration nursing programmes and GPs in both generalist and specialist dementia units. Family caregivers in this study highlighted the need for trust in the care setting staff to adequately care for their relative and reduce the need for hospitalisation. If palliative care is to be implemented and sustained with the independent sector then there is a need for a continuous education and training programme and a commitment to the continued evaluation of end of life care within nursing homes. The 'six steps' programme from the NW NHS End of Life Care programme for Care Homes (NHS NW EoLCP, 2011) is a good

example of such as strategy but requires additional resources to adequately support generalist staff to facilitate the dignified death of residents in their preferred place throughout the UK.

5.5.2 Implications for Practice

Deciding when and if to withdraw active treatment and interventions and opt for comfort care has ethical implications, especially for the health care professionals who are obliged to make them 'in the best interests' of the person. Ethical care is also about not subjecting individuals to unnecessary and sometimes painful and distressing investigations and treatments because of uncertainty about the diagnosis and potential repercussions to the medical or nursing individuals.

Care pathways such as the GSF and LCP (DH, 2008) can provide some guidance and reassurance for care setting staff in long term care units when planning and delivering palliative care to residents. Dementia does not always fit comfortably into generalist care pathways due to the unpredictable and complex nature of the disease. Care pathways need to be flexible enough to provide guidance but not diminish the clinical judgements of suitably qualified and trained professionals in dementia care.

ACP can have a beneficial role to play in having discussions much earlier in the disease trajectory. Ideally this should be initiated with the actual sufferer. However for advanced dementia this is not always possible for a variety of reasons; delay in the diagnosis may not have allowed the person to discuss their future care before cognitive loss has presented; reluctance from clinicians to discuss ACP may also be a factor; and a lack of public awareness of the role of ACP. However national and

international campaigns are underway together with initiatives and information to guide GPs to discuss ACP as well as the need to diagnose dementia at an early stage and promote the role of dementia within the community (WHO, 2012; Alzheimer's Society, 2012; NCPC, 2012; GSF, 2011; RCP, 2009). Sustainability and momentum is essential for ACP to become part of everyday practice.

With or without an ACP completed by the resident, these discussions allow care setting staff an opportunity for family caregivers to achieve some understanding of the disease and what to expect. The discussions also allow the family caregivers an opportunity to talk openly about their fears and anxieties and allow for discussions with other family members either to seek confirmation and reassurance of their thoughts and wishes or find alternative options and opinions from others. In this study, trust in the care setting staff was an essential requirement to allow these sensitive discussions to take place. A genuine commitment to care, compassion for their relative and empathy for their own grief were cited as skills that health and social care professionals require for end of life care and ACP discussions. Health and social care professionals should not see people with dementia in isolation to their family caregivers (DH, 2012).

5.5.3 Implications for Research

At present and despite increasing attention to the needs of people with dementia, there remains a complex range of factors underpinning the need for urgent improvements in service provision, which includes end of life care (WHO, 2012; Alzheimer's Society, 2012; DH, 2011c). Attitudes of all health and social care professionals play an important role in the successful implementation of any strategy and therefore they

should be examined in more detail. This includes the acknowledgement of dementia as a terminal illness, early diagnosis and referral, reducing the stigma of dementia and improving access to education and training.

The diagnosis of dying remains difficult and although care pathways are useful, dementia does not 'fit' into a cancer model of care. The dying phase is much longer and therefore any care pathway must take this into consideration and calls for regular review and assessment of the needs of the person for what may be weeks before the person actually dies (Higgins, 2010; Hughes, *et al.* 2007; Partington, 2005). There is a need to develop care pathways specific to meet the needs of people with advanced dementia as has been done for advanced kidney disease (NHS, EoLC, 2009). The LCP (Ellershaw and Wilkinson, 2011) was developed to promote the best of hospice care to generalist settings and has been widely accepted for cancer patients within mainstream practice in the UK (NICE, 2004). However any care pathways relating to the palliative care needs of people with advanced dementia need to be researched and evaluated for compliance and consistency amongst health professionals.

Conflicts and concerns arise due to the lack of available evidence on when to withdraw active interventions and treatment. This may cause difficulties with diagnosis, particularly for those in the later stages of the disease (Houttekier, *et al.* 2010; Mitchell, *et al.* 2009; van der Steen, 2009a). Concerns expressed include; when analgesia should be administered, and those decisions relating to hydration and nutrition which often contributes to the ethical dilemmas for health care professionals when the resident/patient presents with swallowing difficulties. Further research is needed to provide ethical guidelines on the consequences of initiating or withdrawing

interventions and treatments to relieve suffering and demystify some of the concerns regarding death by starvation and dehydration.

Bartlett and O'Connor (2010) suggested that the medicalisation of dementia has two important benefits, it generates research and scientific interest and it has led to a clearer recognition of the family's role in providing care. The impact of any education and training interventions for family caregivers and the consequences for people with dementia needs further examination. This will confirm what is successful to improve the skills and knowledge of future family caregivers much earlier in the disease trajectory, and also to examine if this impacts upon the potential to delay admission to long term care. Dementia is no barrier to socio-economic status or educational attainment and this should also be researched to examine what implications this has on how people cope with this disease and respond to any future interventions from health and social care professionals.

Attitudes to ACP require further investigation, as failure to implement this early in the disease trajectory of dementia can have an impact on how the person is cared for at the end of life (Addicott, 2010). Individuals, diagnosed with dementia, should be encouraged to discuss their own care needs as early as possible to ensure they are the architects of their own future care plans. ACP as interpreted by family caregivers needs a more wide reaching study to explore the issues identified in this thesis to examine if ACP can, and does, impact on end of life care decisions, actual care delivery provided and the choices people make about their preferred place of dying.

The transitional role of the family caregiver following years of care prior to admission to long term care is also worthy of further research. The grief anxiety does not end with admission and can result in further distress and anxiety (Cairns, 2012; Bergman, *et al.* 2011; Chang and Schneider, 2010). Identifying good practice on how family caregivers, particularly the spouse, are supported in all care settings including home care should be the focus of a longitudinal study to demonstrate the impact of support, education and skills training on the grief anxiety up to the point of, and after, the death of their relative with dementia.

5.5.4 Summary of Chapter Five

The family caregiver has witnessed the slow deterioration of the person with dementia which may have been over several years. This includes the decline in functional ability, together with cognitive decline and communication loss, the admission to long term care, the uncertainty of when their relative is entering the terminal phase and the extent to which active interventions become futile. Difficulties with diagnosis of the disease, poor experiences of hospitalisation and lack of support throughout the disease may contribute to the anxious discussions with medical and nursing staff. Guilt and grief also contribute to the anxiety of trying to do the right thing and making sure their relative is protected from harm.

ACP has a role in the care of people with advanced dementia. Discussing decisions in advance has the advantage of alerting the family caregiver to the potential difficulties experienced during the advanced stage of the disease. Family caregivers accepted that this was something they should know so as to prepare for the inevitable deterioration of their relative. The stress and anxiety of the dementia journey does

not end, nor is it abdicated by the family caregiver, despite the admission to long term care. Distress and discomfort during discussions and decision making were commonplace amongst the family caregivers as they struggled to make the right decisions with or without other family members' input. The trust in the care staff allowed for the ACP discussions to be facilitated within the care setting and it also allowed for family caregivers to have open and honest discussions. Trust is an essential factor for family caregivers if ACP is to take place.

Despite the positive caring experiences within the care setting some family caregivers did have reservations about the continuity of care at different times and with different staff, suggesting a lack of continuity of care that they had witnessed, or as a result of previous experiences in other settings. Family caregivers continued to express responsibility and duty towards their relatives' experience despite being in long term care environments. Residents with advanced dementia in nursing homes cannot be seen in isolation to their family caregivers.

Emerging issues that contributed to the need for ACP discussions, the implementation and the success of end of life care, were numerous and complex. There were several issues that were identified which included; previous experience of hospital care, staff training and education in dementia, communication skills of health and social care professionals, and the lack of time to adequately care and meet the needs of people with dementia. The role of the hospital for delivering palliative care to their relative was expressed in all cases as something that should be avoided and suggested previous experience of hospital care was influential in this opinion.

If ACP is to become a part of routine care then professionals need sensitivity and a sound knowledge base on which to be able to discuss the disease trajectory and likely consequences for the person with dementia as they deteriorate. Family caregivers are susceptible to high levels of anxiety and emotions and should be encouraged to be involved in ACP, but only as much as they feel they can be. The composite case clearly identified what appeared to work well to facilitate ACP discussions between care setting staff and family caregivers and this should help to inform future good practice. This composite case also illuminates priorities for staff training and education so as to develop their knowledge and skills in ACP with family caregivers.

Chapter 6:   Conclusions and Recommendations

6.1 Introduction

This study described the use of ACP from the perspective of the immediate family caregivers of people with advanced dementia who are at the end of life and the professional care staff who facilitate these discussions.   This included their interpretation, observation and the experience of the ACP process.

This study has directly examined the experiences of being asked to inform documentation and decisions for ACP for their relative with dementia.   Family caregivers are often the best people, in the circumstances, to inform health professionals on what the person with advanced dementia may have wanted. Without an understanding of this experience it is difficult for health professionals to organise, implement and deliver an approach to facilitating ACP in practice.

The findings discussed in the previous chapter addressed the study objectives and provided examples of how ACP was facilitated and how this impacted upon the family caregivers' experience of dementia and the care of their relative in a care home. This chapter presents the conclusions from the study and the recommendations for future policy, practice and research for people for people with advanced dementia and their family caregivers.

6.2 Reflections on the Literature

There is growing recognition that people with dementia are entitled to palliative care. In the later stage of the disease most people are not able to communicate their preferences which may leave them at an increased risk of symptom burden and

prolonged suffering. Hospitalisation is not an uncommon practice, in part due to the difficulties with prognostication for people with dementia. A lack of understanding of the disease trajectory and a lack of a palliative care approach is cited in the literature as being one of the main barriers to effective end of life care for people with dementia, (WHO, 2012; van der Steen, 2009a; Di Giulio, *et al.* 2008).

Anxiety of care setting staff to make appropriate decisions and adequately manage symptoms of the dying person was often associated with medical interventions and aggressive treatment regimes. There is some suggestion within the literature that ACP can reduce some of the burden of decisions regarding end of life care and treatment for people with dementia, however it was also accepted that ACP was not part of routine practice.

6.3 Composite Case for the Management of Advance Care Planning Discussions with Family Caregivers.

The composite case highlighted a number of factors that can impact upon the success or failure of ACP discussions with family caregivers. Adequate education for both family caregivers and care setting staff would appear to be a prerequisite to promote structured and detailed discussions in ACP. An understanding of dementia and honest and open communications are essential to facilitate a foundation of trust, sharing responsibilities and mutual respect with both and between family caregivers and care setting staff in the nursing home. Given the accepted levels of distress and caregiver burden of proxy decision makers the composite case gives credence for the need to prepare adequately for ACP discussions. This preparation does not just include family caregivers but also the care staff and professionals who may be

involved in facilitating the ACP discussions. The composite case has given the key points that will be drawn upon to inform the following conclusions to the study.

6.3.1 Empowering Family Caregivers

Empowering family caregivers to complete ACP documents required several sessions with the nursing home staff, followed by a review of the ACP to ensure a good understanding and readiness for end of life care discussions. What was important to caregivers in this study was also mirrored in the response from care setting staff that acknowledgement of the dementia journey being influential is a starting point for ACP discussions. Care setting staff acknowledged that ACP was an individual process and should not be hurried. It must be managed using the knowledge and relationship with each individual family caregiver or family group, together with a knowledge of the legal and ethical framework surrounding ACP documentation.

The inclusion of the previous experiences of the dementia journey in ACP discussions allowed for the identification of gaps in knowledge and understanding and also allowed the family caregiver to express their own grief and anxieties with nursing home staff. Family caregivers needed information and/or opportunities to be supported in their own grief and bereavement at different stages of the dementia journey, but unfortunately family caregivers were not assessed routinely for their grief anxieties or referred for assessment with other services or health and social care professionals.

What ACP did provide was a platform for family caregivers to confront their understanding of the end of life care that may be required for their relative before any crisis event. Dying with dignity was an important feature of the ACP discussions for

family caregivers and cited the need for the resident to die in the care home rather than in a hospital setting. ACP included the discussion of complex nursing and medical interventions to relieve suffering or prevent undue distress in the dying resident, some of which were not familiar to the family caregiver. To do this the ACP facilitator needed to assess the current level of knowledge of the disease trajectory that the family caregiver has. Family caregivers needed encouragement to ask the right questions during ACP as without additional knowledge of the terminal stages of dementia this would have been compromised.

Competencies for ACP also extend to the delivery of end of life care in the last few weeks and days of life. Family caregivers needed support and reassurance that their relative would be cared for in an appropriate way. Contribution and involvement in the end of life care pathway was important for family caregivers as a medium for keeping informed and up-to-date. Discussing sensitive issues prior to the terminal phase of the disease is challenging for care setting staff. The additional education and training opportunities provided to care setting staff which also allowed them to discuss their concerns and anxieties did appear to have a beneficial influence on ACP discussions. Care setting staff felt more confident to discuss death and dying with family caregivers but for sustainable practice to be facilitated education and training should be ongoing and evidence based.

What was very clear from the family caregivers in this study was the emphasis on trust in the care setting to deliver compassionate, empathetic, person centred care and to be knowledgeable in the management of dementia behaviours. The personality and attitude of care staff was important for positive ACP discussions. A communication

style that supports open and honest information was essential to develop this trust and reduce the potential for conflict.

6.3.2 Barriers to Advance Care Planning Discussions with Family Caregivers

Barriers to ACP completion were confirmed in the deviant case who demonstrated denial and a lack of understanding of the dementia journey and the need for appropriate and timely discussions. Earlier diagnosis of dementia would exclude reversible causes and allow earlier access to services and therapeutic interventions for people with dementia and their family caregivers. As previously identified in chapter six, ACP is often not initiated early enough in the disease trajectory of dementia, which in part is due to the difficulties with diagnosis and partly as a result of inadequate service provision and lack of agreement over the terminal course of the disease (WHO, 2012; van der Steen, 2009a; Di Giulio, *et al.* 2008).

A staged introduction is preferred for some family caregivers who have difficulty accepting ACP and the terminal characteristics of the disease. Family caregivers stated that ACP was an individual issue and should only be commenced when the family member was ready to discuss it. This suggested that some family caregivers needed time to reflect on the meaning of ACP and seeking out the opinions or approval of other family members sometimes offered insights into what previous discussions had taken place. This was also confirmed by the staff in the care settings and supported the need for ACP discussions much earlier in the disease trajectory.

It must be acknowledged that family caregivers have experienced different practices from professional care staff during their role as carer and this may add to

misunderstandings and anxieties about what are acceptable and/or unacceptable care practices.

The change in role for the family caregiver, following admission to a nursing home, should be given more than lip service by health and social care professionals. Misunderstandings due to knowledge deficits and unresolved grief can impact upon ACP outcomes and it is essential that this is acknowledged by care setting staff. Assessment of the family caregivers' anticipatory or pre-death grief needs to be addressed on admission to the nursing home or at some stage prior to the ACP completion, however this will require additional education and training by care setting staff.

Death could have been anticipated for several months or weeks due to the unpredictable nature of the disease so it was important that family caregivers were aware of this in advance in order to avoid anxieties and misunderstandings. Grieving has been a long term process for most family caregivers of people with dementia and this must be recognised by health and social care professionals. A lack of acknowledgement by care setting staff for bereavement care and/or counselling at different stages, which were not routinely discussed before or after the death of the resident, can cause additional stress and anxiety for the family caregiver.

Family caregivers and care setting staff (including physicians) who are reluctant to accept the terminal nature of dementia or who fail to recognise the benefits of a palliative care approach can impact on the necessity for hospitalisation at the end of life for the resident with dementia. This also includes the reluctance of care setting

staff to engage with sensitive discussions due to their own feelings of inadequacy and/or scepticism.

6.4 Supporting Change in Practice to Facilitate Advance Care Planning

The importance of ACP is being increasingly recognised, especially to those people with life limiting illness. There is a growing interest and body of knowledge from the international community that ACP can contribute to care choices chosen to meet the needs of people in the advanced stage of disease. ACP is reliant on the communication skills of the trained professional facilitator who needs to have an understanding of the legal aspects, the terminology, be knowledgeable about the specific disease and be able to clarify palliative and end of life care.

The Department of Health (2009b) identified common core competencies and principles for health and social care workers with adults at the end of life. Communication is a core clinical competency. These competencies set out expectations and skills which are appropriate for different levels of health care practitioners. The expectation is that ACP will develop into a shared decision making process, initiated earlier in the disease so an ongoing discussion can be facilitated to promote patient choice as much as possible. This is particularly relevant for people with dementia who may be several months or years into the disease before a confirmed diagnosis is made. In the absence of an ACP completed by the person themselves then the family caregiver may be called upon to identify and support the care choices made on their behalf and should be given the same level of support and consideration.

ACP has the potential to help people prepare for future changes in their health status as well as prepare for death. This would be assisted by a more public education campaign similar to the National Council of Palliative Care 'Dying Matters' campaign to raise public awareness (NCPC, 2012). This would encourage families to discuss death and dying as routine matters, allowing the family caregiver to give a more accurate representation of their preferred choices if lack of capacity becomes an issue.

The current economic climate has implications for the provision of adequate resources for palliative care for people with life limiting conditions. Palliative care is labour intensive and time consuming and if it is to be sustained and developed in all settings it requires a commitment to the provision of sufficient/adequate resources which includes; adequate numbers of nursing and care staff, appropriate and timely education and training, and access to specialist personnel and equipment, which includes out of hours provision.

6.4.1 Recommendations for Policy

- Access to timely diagnosis and referral to a range of support services should be a priority for people with dementia.

- ACP must be a voluntary process and the wishes of those who choose not to be involved should be respected. Family caregivers should be encouraged to participate if the person lacks capacity but only when they are ready and willing to do so.

- ACP should be facilitated earlier in the disease trajectory following dementia diagnosis so as to ensure their needs are adequately represented once capacity is lost.

- ACP must follow an ethical and legal framework clearly expressed in terms of policy and practice.

- Family caregiver' needs should be formally assessed before and following admission to long term care of the person with dementia.

- Grieving has been a long term process for most family caregivers of people with dementia and this must be recognised by health and social care professionals. Access to appropriate counselling and/or bereavement services is essential if required.

- There is an urgent need for a national educational intervention strategy for people with dementia and their family caregivers to enable them to live for longer in the community.

- Nursing home care providers for residents with dementia should receive additional education and training and have access to specialist practitioners for dementia and palliative care. There should also be an improved quality monitoring system to ensure family caregivers have access to support and advice on choosing appropriate care settings for their relative.

- People with dementia and their family care givers should have the option to engage with appropriate interventions to improve their understanding of the disease and to anticipate and manage changes in care needs.

6.4.2 Recommendations for Education and Practice

- ACP should always reflect the person's personal choices and preferences or if they lack capacity should indicate their best interests.

- All people must be given an opportunity to consider their best options for future care provision, regardless of the disease. This includes the empowerment of individuals or family caregivers to enhance shared decision making and develop relationships.

- ACP should be a flexible document as people's priorities and preferences change over time.

- ACP must be sensitive to the cultural and religious differences that reflect the demographics of a country.

- Health and social care professionals need to acknowledge and develop their own skills in relation to communication skills and knowledge of specific disease trajectories.

- Family caregiver's role in ACP should be acknowledged and supported and be given due consideration to their own needs influenced by grief and anxiety.

- Continuous education and training in ACP should be available to all health and social care professionals and be included in undergraduate medical and nursing programmes.

6.4.3 Recommendations for Research

- The use of specific and/or generic end of life care pathways for dementia needs to be developed and evaluated to examine if they are used consistently within a variety of care settings and how they impact upon the quality of dying for people with dementia

- Development of an ACP pathway that is evidence based, adaptable and user friendly for use in a variety of care environments.

- Interpretation and application of the Mental Capacity Act (MCA, 2005) in relation to ACP needs further exploration to ensure this is used appropriately and consistently to safeguard the interests of vulnerable people.

- The application and impact of Lasting Power of Attorney (welfare provision) on family caregiver experience of the dementia journey.

- Research the impact of current local intervention strategies on family caregiver management of their relative with dementia to inform practice development.

- Examine the impact of using grief assessment tools for family caregivers at different stages of the dementia journey.

6.5 Contribution to Knowledge

Many previous studies have been concerned with the motives or rationale of the decisions / actions made by the family caregivers when decision making for people with advanced dementia. ACP was not always referred to as a structured document and there were issues relating to the completion of documents and health professionals' expertise or willingness to participate in these discussions at the advanced stage of the disease.

This research, as identified by the composite case, adds to the body of knowledge by confirming how ACP can be facilitated with the family caregiver in the context of everyday practice within the nursing home environment for older people with dementia. Dying with dignity was an important feature of the ACP discussions for family caregivers and cited the need for the resident to die in the care home rather than in a hospital setting. Some of the resident's previous preferences, for example, music, were important features of the dying ritual for family caregivers. This suggested that to family caregivers ACP is more than discussing the medical and nursing goals or outcomes of care. Anticipation of physical symptoms needs to be discussed during ACP and not left until the resident had deteriorated. The readiness to participate in ACP discussions needs to be assessed and confirmed by care setting staff with family caregivers. Communication and interpersonal skills required by care setting staff were essential skills to facilitate ACP.

The findings also highlighted the importance of how care setting staff need to make emotive links with family caregivers to support them in their ACP discussions. Grieving has been a long term process for most family caregivers of people with

dementia and this must be recognised by health and social care professionals who should have expertise in how to refer family caregivers to appropriate counselling and/or bereavement services if required.

This study also contributes to the ongoing debate which supports the view that ACP should be introduced much earlier in the disease trajectory of dementia. Introducing ACP from diagnosis onwards could incorporate the supported decision making model as recommended by WHO (2012). The involvement of the person with dementia as much as possible at every stage of decision making is essential from the diagnosis to the advanced stage. When capacity is eventually impaired, those supporting the person, including family caregivers, should have a good understanding of their care preferences and wishes as they approach the end of their life, and are in a better position to determine what the person would have wanted (WHO, 2012).

If ACP is to become a part of routine care then professionals need sensitivity and a sound knowledge base on which to be able to discuss the disease trajectory and likely consequences for the person with dementia as they deteriorate. Family caregivers are susceptible to high levels of anxiety and emotions and should be encouraged to be involved in ACP, but only as much as they feel they can be, and this supports the need for staged discussions.

Global projections indicate that the total number of people with dementia will double every twenty years to 65.7 million in 2030 and 115.4 million in 2050 (WHO 2012). Despite the tragedy of dementia, the challenges of diagnosis and the inequity of access to support services, treatment and care, there are clear indications that

dementia has moved into mainstream public and political consciousness. There are also clear indications that a sensitive, compassionate, knowledgeable and coordinated workforce can have an impact upon the quality of life and on the dying of the person with dementia. ACP that is facilitated successfully empowers the person with dementia and/or their family caregiver, to make informed choices about their future care needs and their preferred place of death.

A family caregiver's experience of ACP prior to the eventual death of their mother summarises the emotional context of the benefit of the ACP process;

> *"I would say, it removed a lot of the uncertainty, that perhaps hadn't the advance planning been done, all of a sudden you'll be faced with a decision, it would be at a time perhaps when you're not emotionally prepared for it, and it would be a bit too much at that stage. At least if you've planned it, I thought it helped, in my case, I discussed what was going to happen, how best end of life can be dealt with in terms of making her life as easy as possible really."*
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A study to explore the experiences of advance care planning amongst family caregivers of people with advanced dementia.

Appendices

Appendix 1: A Summary Table of the Literature

Author	Year	Country	Title of the study	Study participants	Setting	Methods	Relevant findings	Limitations
Section 2.2								
Coetzee, *et al.*	2003	UK	The attitudes of carers and old age psychiatrists towards the treatment of potentially fatal events in end-stage dementia.	148 Carers 34 Medical Students recruited from medical school and Alzheimer's society	Nottingham	Questionnaire / survey	Clinicians favoured active treatment of potentially fatal events in end stage dementia less than carers who valued patient centred issues such as dying with dignity.	Further work required to identify factors which may influence family caregivers and health professionals' attitudes on when to initiate a palliative care approach.
Di Giulio, *et al.*	2008	Italy	Dying with Advanced Dementia in Long Term Care Geriatric Institutions: A Retrospective Study	141 patients with advanced dementia	Seven long term care institutions	A retrospective exploratory study on patients who died in the previous 12 months.	No confirmed consensus of definition of terminality. High prevalence of bed sores. Aggressive treatment of severe demented patients. Dementia no confirmed as a cause of death. Total absence of advanced directives	The reliance on documentation within the study and issues of accuracy and inconsistency between health professionals is a consideration.
Goodman, *et al.*	2010	UK	End of Life care for community dwelling older people with dementia: an integrated review			Integrated literature review	68 papers included (1995-2006). Research on end-of-life care for people with dementia has yet to develop interventions that address the particular challenges that dying with dementia poses.	

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Author	Year	Country	Title	Sample	Setting	Method	Findings	Limitations
Houttekier *et al.*	2010	Netherlands	Place of Death of Older Persons with Dementia. A Study in Five European Countries.	Death certificates data on all deaths in 2003 of people aged 65 and over	European countries; Belgium, Netherlands, England, Scotland, Wales.	Multivariate analysis of death certificates	Place of death from dementia differed significantly between the countries. In all countries the majority of patients died in long term care facilities.	Reliance on accuracy of documentation and death certificates.
Lloyd-Williams and Payne	2002	UK	Can multidisciplinary guidelines improve the palliation of symptoms in the terminal phase of dementia?	Examined 27 deaths occurring in a long stay unit	Large Psychiatric Hospital	Retrospective Audit	The findings support the use of guidelines, developed in collaboration with the multidisciplinary team, for improving palliative care for non-oncology patients.	Further work required to understand the full potential of a MDT approach to palliative care across different settings.
Mitchell, *et al.*	2004a	USA	Estimating Prognosis for Nursing Home Residents With Advanced Dementia	All patients admitted with dementia between June 1st 1994 and Dec. 30, 1998	Medicare and Medicaid Nursing Homes in New York.	Retrospective cohort study from the Minimum Data Set (MDS)	A risk score based on 12 variables from the MDS estimates 6-month mortality for nursing homes residents with advanced dementia. And includes; CVS;DM; Poor nutritional states, older age; male; functional impairment.	Reliance on accuracy of documentation. Funding arrangement of medicare and Medicaid and admission criteria may be not generalisable.
Mitchell, *et al.*	2007a	USA	Decisions to Forgo Hospitalisation in Advanced Dementia: A Nationwide Study	Nursing Home residents with advanced dementia	All Medicare and Medicaid certified nursing homes in 48 US states	Multilevel, multivariate, logistic regression study to examine hospital referral features	Directives to forgo hospitalisation for US Nursing Home residents with advanced dementia are uncommon.	Reliance on accuracy of documentation. Funding arrangement of Medicare and Medicaid and admission criteria may be not generalisable.

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Mitchell, *et al.*	2007b	USA	Hospice Care for Patients with Dementia	Data describing hospice decedents in 2005	Hospice	Survey	To be eligible for hospice, patients must have an estimated life expectancy of less than six months.	Reliance on prognostic reliability and accuracy of documentation.
Mitchell, *et al.*	2009	USA	The Clinical Course of Advanced Dementia	323 Nursing home residents	22 Nursing Homes, Boston	Chart reviews, interviews with nurses, physical examination. After death analysis.	In the last three months of life 40.7% of residents underwent at least one burdensome intervention; hospitalisation; parenteral therapy; tube feeding. Residents whose proxies had a good understanding of the poor prognosis were less likely to have burdensome interventions.	The results were based on quarterly reviews of notes and interviews with nurses rather than observations of patients. Episodes of distress may have been missed and the paper did not comment on the quality of care.
Nakanishi and Honda	2009	Japan	Process of decision making and end-of-life care for patients with dementia in group homes in Japan	33 Family caregivers	Care settings, including nursing homes	Case studies	When family caregivers are involved in the decision making process this can affect decisions relating to reduce hospitalisation and the need for invasive tube feeding.	Retrospective collection of data which may cause selection bias. Data gained may not be generalisable to all facilities in Japan. Information on quality evaluations of end of life care was not collected.
Sampson, *et al.*	2012	UK	Improving end of life care for people with dementia: a rapid participatory appraisal	50 health and social care professionals. 7 family caregivers	Acute hospital, care homes and Mental Health Trust	Case note audit. Economic analysis. Interviews and focus groups	End of life care was fragmented and adhoc leading to crisis and inappropriate hospital admission. Acute	Focus groups may have influenced the participants to hold views consistent with other participant rather than hold a

Author	Year	Country	Title	Setting	Sample	Study Design	Findings	Limitations
							hospital admission was common in the last six months of life. No record was found of the palliative care team involvement and none had documentation of their spiritual needs or an ACP. Identified the need for an integrated dementia pathway.	different viewpoint. Limited number of family caregivers recruited.
Van der Steen	2010		Dying with Dementia: What We Know after More than a Decade of Research.			Literature Review	Guidelines for care and treatment support the benefits of advance care planning, continuity of care, and family and practitioner education	
Section 2.3								
Brandt, *et al.*	2005	Holland	The last days of life of nursing home patients with and without dementia assessed with the Palliative care Outcome Scale.	16 Dutch nursing homes	Patients with a life expectancy of six weeks or less	A prospective observational study	POS non scores (not applicable, not known) were mainly found in the psychosocial and spiritual domains, particularly for those with dementia. Mean scores for non demented patients were favourable for the majority of POS items.	The study relied on the reports of proxies namely caregivers. The proxies may have under or over reported the patient's symptoms.

	Year	Country	Title	Participants	Care settings	Qualitative design	Findings	Limitations
Casey, *et al.*	2011	Ireland	Dying well: factors that influence the provision of good end-of-life care for older people in acute and long stay care settings in Ireland	33 Managers and Stakeholders		Qualitative design	The philosophy, culture and organisation of care are influential factors on the quality of care received by older people.	The study relied on the reports of managers. The managers may have under or over reported the patient's symptoms.
Chen, *et al.*	2010	Taiwan	Validating nurses' and nursing assistants' report of assessing pain in older people with dementia.	304 older people with dementia 15 registered nurses 21 nursing assistants	Six dementia special care units in Taiwan	Four item pain inventory and Doloplus-2 scale to investigate different raters pain reports.	Pain inquiry and behavioural observation should be performed routinely as the fifth vital sign for developing effective care plans.	People with dementia may have varying degrees of cognitive impairment and may influence the results and generalisability of the study. Stratifying the sample based on cognitive status is suggested for future studies.
Di Giulio, *et al.*	2008	Italy	Dying with Advanced Dementia in Long Term Care Geriatric Institutions: A Retrospective Study	141 patients with advanced dementia	Seven long term care institutions	A retrospective exploratory study on patients who died in the previous 12 months.	No confirmed consensus of definition of terminality. High prevalence of bed sores. Aggressive treatment of severe demented patients. Dementia not confirmed as a cause of death Total absence of advanced directives	Reliance on documentation within the study. Issues such as level of accuracy and consistency should be considered.
Fargeau, *et al.*	2010	France	Alzheimer's disease and impairment of the Self	47 patients with mild to moderate Alzheimer's disease.	University Department of Neurology, de Poitiers, France	Semi structured scale designed to assess the self-concept along three dimensions: Material self, the social self, and	The majority of patients presented impairment in at least one dimension of the Self. The severity of the Self was correlated to the	Small study. There is a need to explore fully the relationship between impairments of the self and clinical variables.

							impairment of memory and apathy.	
Formiga, *et al.*	2007	Spain	Dying in hospital of terminal heart failure or severe dementia: the circumstances associated with death and the opinions of caregivers	102 Patients dying from heart failure or dementia and their family Caregivers	Two Spanish acute tertiary hospitals	Evaluation of patient medical records. Questionnaire to family caregivers	Some aspects of palliative care provided to elderly patients with end stage chronic disease could be improved; symptom control and information provided to family caregivers.	A lack of data when directives limiting aggressive care were incorporated in the course of the disease was not collected.
Jeong, *et al.*	2012	Australia	Gerotranscendence: The Phenomenon of Advance Care Planning.	3 x Residents 11 x family members 13 Registered Nurses	Three Residential Care facilities.		ACP facilitated the older person to continue to realise 'the essence of their being'. Increased vigilance to factors that influence decision making will enable best care outcomes.	Small sample size. The authors identified that the values clarification worksheet may require further testing and revision.
Lamberg, *et al.*	2005	USA	Decisions to Hospitalise Nursing Home Residents Dying with Advanced Dementia.	240 Residents who died between Jan 2001 and Dec 2003	675-bed Nursing Home, Boston, Massachusetts.	Retrospective cohort study	Hospital transfers were common during the last six months of life. A decision to forgo hospitalise is not made until death is imminent.	Limited to the cohort under study and accuracy of documented evidence.
Mast, *et al.*	2004	USA	End-of-Life Treatment Guidelines for Life-Limiting Disease.			Four Nationally developed clinical guidelines were assessed	Ten per cent of guidelines had significant palliative care content. The least addressed domain dealt with spirituality, ethics, and advocacy and family roles.	The variation in guidelines was indicative of the search strategy and guidelines with more palliative care content as opposed to specific diseases may have been included.

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Author	Year	Country	Title	Sample	Setting	Method	Findings	Comments
McCarthy, et al.	1997	UK	The Experience of Dying With Dementia: A Retrospective Study.	170 dementia patients compared with 1513 cancer patients	20 English health districts	Retrospective sample survey	Patients dying from dementia have symptoms and health needs comparable with cancer patients. Greater attentions should be given to these needs.	The study was retrospective from informal careers (several months after the death) which could question the validity of the findings.
Parsons, et al.	2010		Withholding, Discontinuing and Withdrawing Medications in Dementia Patients at the End of Life. A Neglected Problem in the Disadvantaged Dying?			Literature review (136 papers)	End of life care is complicated due to the difficulties in accurately estimating life expectancy. Results in difficult ethical considerations regarding withholding or withdrawing treatment.	
Seymour, et al.	2002	UK	Good deaths, bad deaths: older people's assessment of the risks and benefits of morphine and terminal sedation in end-of-life care.	32 participants	Six purposive community groups	Eight Focus Group	Participants understood an idealised death in which morphine administration and terminal sedation serve to provide dying people with an easy, comfortable and quiet death.	Focus groups settings may have influenced the participants to hold views consistent with other participant rather than hold a different viewpoint.
Shega, et al.	2003	USA	Palliative Excellence in Alzheimer Care Efforts (PEACE): A Program Description	150 older adults and families	Windermere Senior Health Centre, Chicago	Interviews	PEACE programme is a disease management model for dementia that incorporates advance planning, patient care, family support	Authors suggest future research should include both a comparison to usual routine care and an accounting of costs for each model.

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Author	Year	Country	Title	Sample	Setting	Method	Findings	Limitations
							and palliative care from diagnosis to terminal phase providing quality care for dementia patients and their caregivers.	
Small, et al.	2009	UK	Dying, death and bereavement: a qualitative study of the views of carers of people with heart failure in the UK.	20 Bereaved carers of older people with heart failure.	GP surgeries in four areas of the UK	Interviews	Dissatisfaction with the manner of the death was focussed around hospital care, particularly what they believed to be futile treatments.	Small study. Recruitment of bereaved carers – the impact of bereavement may shape the way they report end of life care. Significant numbers of people did not respond or declined to be interviewed – their views may have differed.
Sloane, et al.	2008	USA	Dying with Dementia in Long Term Care.	677 staff 451 family carers	199 Residential care facilities 31 Nursing homes in Florida	After death Interviews	Dying residents with dementia tended to die less often in a hospital, have less shortness of breath, and receive more physical restraints and sedative medications. Persons dying with dementia in residential settings tended to have more skin ulcers and poorer hygiene	The use of proxy respondents and the potential for underreporting.
Van der Steen, et al.	2009b	Holland	Discomfort in dementia patients dying from pneumonia and its	559 Pneumonia patients 166 patients with intake problems who	61 Nursing Homes	Observation using Discomfort Scale – Dementia of Alzheimer's Type	Death from pneumonia may cause suffering in dementia patients.	Further confirmation is required in prospective studies with different case

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	Year	Country	Title	Participants	Setting	Method	Findings	Comments
			relief by antibiotics	had no pneumonia.		(DS-DAT)	Antibiotic treatment was associated with less discomfort before death. Invasive rehydration was associated with more discomfort.	mix, antibiotic treatment and other treatments to relieve symptoms. The need to explore medical and ethical issues amongst professionals is suggested.

Section 2.4

	Year	Country	Title	Participants	Setting	Method	Findings	Comments
Barrio-Cantalejo, *et al.*	2009	Spain	Advance Directives and Proxies' Predictions About Patients' Treatment Preferences.	171 pairs of patients and their proxies	Six primary care centres and a nursing home in Granada	Life Sustaining Preferences Questionnaire	Promoting communication between patients and their proxies improves the accuracy of proxies' predictions much more than isolated advance directive forms.	
de Boer, *et al.*	2011	Holland	Advance Directives for Euthanasia in Dementia: How Do They Affect Resident Care in Dutch Nursing Homes? Experiences of Physicians and Relatives.	110 Physicians 8 Relatives	Nursing Homes	Questionnaires and Interviews	Advance directives for euthanasia of people with dementia were rarely adhered to. However they appear to have a supportive role in setting limitations on life-sustaining treatments.	Possible recall bias in the responses of physicians when asked about their last case – only the last cases were selected.
Detering, *et al.*	2010	Australia	The Impact of advance care planning on end of life care in elderly patients: randomised controlled trial.	309 legally competent medical inpatients aged 80 or more (six months prior to death)	University Hospital in Melbourne.	Prospective randomised controlled trial	Advance care planning improves end of life care and patient and family satisfaction and reduces stress, anxiety and	A comparison to usual routine care and an accounting of costs for the interventions may be useful for future studies in different

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	Year	Country	Title	Sample size	Setting	Study type	Findings	settings and cultures.
Dobalian	2006	USA	Advance care planning documents in nursing facilities: Results from a nationally representative survey	5899 residents	815 Medicare or Medicaid Nursing Home facilities	Retrospective Cohort Study	Most residents (especially those with dementia) were less likely to have advance care plans. ACP may help to limit the discontinuity of care that may exist when a nursing home resident is sent to hospital and his or her preference for care is unknown.	Limited to the cohort under study and accuracy of documented evidence.
Dwyer, *et al.*	2010	Sweden	Nursing home residents' views on dying and death: nursing home employee's perspectives	20 employees	4 Swedish Nursing Homes	Focus Groups	A deeper understanding of the palliative care philosophy is needed to further develop and meet the needs of the dying resident in nursing homes.	Focus groups settings may have influenced the participants to hold views consistent with other participant rather than hold a different viewpoint.
Engel, *et al.*	2006	USA	Satisfaction with End of Life Care for Nursing Home Residents with Advanced Dementia.	148 Nursing Home residents aged 65 and older with advanced dementia and their health care proxies.	13 Nursing Homes in Boston	Cross- sectional study	Better communication, greater resident comfort, no tube feeding and care in a specialised dementia unit are modifiable factors that may improve satisfaction with care in advanced dementia.	The study participants were almost all white. Detailed information was not available about the ACP process. Health care practitioners may not have precisely remembered how long they spent discussing advance directives.

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Froggatt, *et al.*	2009	UK	Advance care planning in care homes for older people: an English perspective.	213 Care Home Managers	Nursing Homes in North west and South West Regions	Questionnaires and interviews	Managers face intrinsic and extrinsic challenges in the implementation of ACP in the care home context. Lack of confidence and knowledge of end-of-life care was cited.	Described as the first descriptive survey of English care home managers about ACP. Provides a baseline but identifies further development of ACP complexities and implementations.
Goodwin and Waters	2009		'In solitary confinement': Planning end-of-life well-being with people with advanced dementia, their family and professional carers.	12 patients and family carer and professional carers	Four hospital wards An acute medical ward for people with dementia, older persons unit and three nursing homes	Observations of residents and interviews; 12 triads patient, family and professional carer.	Patients with advanced dementia in this study were able to express views on the end of life care. Suggesting a general underestimation of the abilities of people with dementia to discuss emotionally charged topics.	Small sample size. Inconclusive. Stratifying the sample based on cognitive status of participants with dementia and the different experience of family caregivers could be suggested for future studies.
Karel, *et al.*	2007	USA	Three Methods of Assessing Values for Advance Care Planning: Comparing Persons With and Without Dementia.	88 men and 88 women over 60 years of age (half of whom had dementia)	Self referred of referred by a caregiver as a result of fliers in Boston	Health care values survey	Adults with and without dementia were reported as being able to respond meaningfully to questions about values regarding quality of life. Older adults with dementia should be included in clarifying values for ACP if they are able.	The tools used in this sample were with people who were mainly White, had a high school education and were healthy enough to travel to a hospital clinic to participate. Other samples of older adults may have responded differently.
Lacy	2006	USA	End-of-Life Decision Making for Nursing Home Residents with Dementia: A Survey of Nursing Home Social Services Staff.	138 Social service staff	Nursing Homes across New York	Survey	Despite advance discussions taking place problems with implementation remain with the appropriate use of interventions.	Sampling methods and response limits were not representative of social service staff in New York. Broad questions in the

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Author	Year	Country	Title	Sample	Selection	Method	Findings	Limitations
							survey were used rather than in-depth questions in specific areas.	
Moorman and Carr	2008	USA	Spouse's Effectiveness as End of Life Health Care Surrogates: Accuracy, Uncertainty and Errors of Overtreatment and Under treatment.	2,750 couples aged mid 60's.	Selected through Wisconsin Longitudinal study in 2004	Scenario based feedback from couples	Suggesting social care staff needs ongoing education and training. Surrogates were accurate in the majority of cases. Errors of overtreatment and under treatment were equally present. Health Care practitioners should facilitate family level conversations to accurately represent end of life preferences.	Issues that could have influenced the results included the AADF form and the lack of experience of being a proxy and the limited range of scenarios used
Moss, et al.	2002b	USA	Terminal Care for Nursing Home Residents with Dementia.	Nursing Home Administrators	400 nursing homes	Postal questionnaire	Nursing homes should recognise the need to be proactive in leading residents, staff and families to think in advance about problems of pain, treatment and comfort care.	Provides a baseline view of nursing homes and administrative staff's perceptions of terminal care for residents with dementia. Distinguishing between ongoing care and terminal care needs to be explored in more detail.
Pearlman, et al.	2000	USA	Preferences for Life-Sustaining Treatments in Advance Care Planning and Surrogate Decision Making.	342 participants	Convenience sample from seven groups of varying age ranges and illness	Interview	Participants chose to forgo more invasive or long-term treatments than less invasive short term treatments.	Convenience sample mostly white and educated than general population.

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Author	Year	Country	Title	Sample	Setting	Method	Findings	Limitations
Rurup, et al.	2006	Netherlands	Attitudes of physicians, nurses and relatives towards end-of-life decisions concerning nursing home patients with dementia.	75 Physicians, 178 nurses and 136 relatives of nursing home patients suffering from dementia for who a decision concerning ANH was made	39 Nursing Homes	Questionnaires	Physicians, nurses and relatives are all guided by the best interest of the patient. Relatives attached more importance to advance directives than physicians and how more permissive attitudes towards hastening death.	Reliance on those participating in the study and to the extent this impacts on care delivery could be further explored in respect of disagreements and the role of ACP.
Sampson, et al.	2008	UK	Palliative care in advanced dementia: a mixed methods approach from the development of a complex intervention.	20 Carers 21 Hospital and primary care staff	London Hospital Trust	Retrospective case note review Interviews	Patients with dementia have complex physical and psychological needs. Complicated care systems make communication between care providers challenging.	Authors accept that we do not know what constitutes a good outcome for patients with advanced dementia who are generally unable to express their needs and wishes. The use of proxies may not accurately reflect patient's wishes when they last had capacity.
Sampson, et al.	2010		Palliative assessment and advance care planning in severe dementia: An exploratory randomized controlled trial of a complex intervention.	33 carers of Patients with severe dementia who had an emergency hospital admission. 21 Health care professionals	Hospital	Pilot study. Interviews with caregivers and health professionals	Only Seven carers made ACP's following the intervention. Despite the fact that care planning discussions were well received there remained reluctance from carers to write ACP's and needs further exploration.	Methodological issues relating to access to carers and GP records of end of life care. Unable to establish reasons for withdrawal. Alternative methodologies may need to be considered.

Samsi and Manthorpe	2011	UK	'I live for today': a qualitative study investigating older people's attitudes to advance planning.	37 self declared well older people	Community based sources in London	Interviews	Four main themes were identified; individual inclination to plan; types of plans; reasons for planning or not planning; and support with planning. There was a lack of awareness of specific principles of the Mental Capacity Act which may have contributed to poor planning.	Limited study and small sample size. Not able to generalise the findings.
Stewart, et al.	2011	UK	Advance care planning in care homes for older people: a qualitative study of the views of care staff and families.	33 care home managers 29 care assistants 18 nurses 10 community nurses 15 family and friends 14 residents	34 Care homes in London	Interviews	Staff and families revealed positive opinions towards ACP. Barriers included; resident's reluctance to discuss ACP; reluctance of HCA to be involved with ACP; residents with dementia; family involvement; and unforeseen medical problems.	The study did not represent the views of general practitioners. Care home residents may not have experienced ACP outcomes compared to staff.
Yeung Sim Jeong et al.	2011	Aus	The essentials of Advance Care Planning for end-of-life care for older people.	Residents, families and nurses	Two teaching hospitals, 20 high care facilities for people over 65 years	Case Study. Observation, interviews and document analysis.	A conceptual framework developed elaborated how ACP should be implemented and what may constitute successful implementation in residential care facilities.	Various prerequisites were required for successful implementation in this Australian study and may not be generalisable elsewhere. The

Author	Year	Country	Title/Focus	Sample	Setting	Data collection	Findings	Limitations
Yung, et al.	2010	USA	Documentation of Advance Care Planning for Community-Dwelling Elders.	ALCOVE 1 372 seniors ALCOVE 2 – 644 Patients.	AlCOVE-1 – two managed care organisations ALCOVE 2- medical groups	Data collected as part of two quality care evaluations; ALCOVE -1 – telephone interview, ALCOVE-2 – telephone interviews	Community dwelling elders' preferences for end-of-life care are not consistent with documentation in their medical records.	Sensitive topics may not be appropriate for telephone interviews. Patients may have misreported what they had discussed. Medical records data may have been lost or not filed. Providers may have been inconsistent in their documentation of ACP topics.
Section 2.5 Albinson and Strang	2003a	Sweden	Existential Concerns of Families of Late-Stage Dementia Patients: Questions of Freedom, Choices, Isolation, Death and Meaning.	20 family members	Nursing homes, one day care centre and one private group dwelling	Qualitative In-depth interviews	The study highlights the importance of not only seeing the physical and psychological caregiver aspects but also the existential ones that emerge when confronting impending death	Small sample size. Not able to generalise findings to other settings and cultures.
Black et al.	2009	USA	Surrogate Decision Makers' Understanding of Dementia Patients' Prior Wishes for End-of-Life Care.	34 surrogate decision makers for hospice-eligible nursing home patients with dementia	Three Nursing Homes	Semi structured interviews	The most commonly reported wish for end of life care was not to be kept alive by 'machines' or 'extraordinary measures'	Dementia patients who participated were too cognitively impaired to be interviewed to determine the accuracy of surrogates reports.
Elliot et al.	2009	USA	Family decision-making in advanced dementia: narrative and ethics.	39 family members of severely impaired nursing home residents in Minnesota	Nursing Homes in Minnesota.	Focus groups	The families in the focus groups used their relative's life stories to frame their decisions for care.	The findings may not be fully applicable to other populations. Although the focus groups reflected the

Author	Year	Country	Title	Sample	Setting	Method	Findings	Limitations
							Narrative ethics may provide clinicians working in primary care understandings of family's perspectives and priorities.	ethnic mix of the region only one participant was not White. Focus groups settings may have influenced the participants to hold views consistent with other participant rather than hold a different viewpoint.
Forbes *et al.*	2000	USA	End-of-Life Decision Making for Nursing Home Residents with Dementia.	28 family members and residents with moderate to severe dementia	Nursing Homes	Focus groups	Five themes were identified that describe the context of decision making; emotional effect; insult to story; two faces of death; values and goals; end-of-life treatments; and the unrecognised trajectory of dying.	Small sample size. Focus groups in the settings may have influenced the participants to hold views consistent with other participant rather than hold a different viewpoint.
Givens *et al.*	2009	USA	Healthcare Proxies of Nursing Home Residents with Advanced Dementia: Decisions They Confront and Their Satisfaction with Decision-Making.	323 Residents and their Health Care Proxies (HCP)	22 Nursing Homes in Boston	Prospective Cohort Study. HCP Completion of the Decision Satisfaction Inventory	Greater decision making satisfaction was associated with the resident living on a special care dementia unit, greater resident comfort and the HCP not being the resident's child.	The health care proxies and residents were mostly white and predominately women and all lived within the Boston area which may limit the generalisability of the findings.
Kellet *et al.*	2010	Aus	Life stories and biography: a means of connecting family and staff to people with dementia.	7 Family caregivers. 7 Care setting staff	Long term care setting	Focus Groups	Family Biography Workshop has potential to improve the relationships between family caregivers.	Pilot study to provide direction for a larger group randomised trial to evaluate the effects of a Family Biography Programme.

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Kiely et al.	2008	USA	Health Care Proxy Grief Symptoms Before The Death of Nursing Home Residents with Advanced Dementia.	315 Nursing Home Residents and their HCP.	Nursing Homes in Boston	Prospective cohort study (CASCADE STUDY)	Separation distress was the most frequently experienced grief symptom amongst HCP's. HCP's would benefit from early intervention to reduce suffering.	Limited to the Boston area – 89% White so not generalisable. Random point in the residents NH stay. The study does not explore the impact of predeath grief on HCP outcomes (bereavement).
Wakunami et al.	2009	JAPAN	Families' acceptance of near death: A qualitative study of the process for introducing end-of-life care.	23 participants	Care settings	Focus Groups and Interviews	Eleven categories emerged. Conceptual model emerged that could be useful in evaluating the families stage of experience in accepting near death of their relative.	Small sample size and Focus groups may have influenced participants to adopt consistent views with other participants. The conceptual model will require further evaluation in practice.

The following reply has been provided by Jo Downing, Information
Officer (Corec)

From: Susan Ashton [dsdd35@hotmail.com]
Sent: 02 October 2008 07:09
To: Ashton, Susan
Subject: FW: query

Attachments: Audit_or_Research_table_Nov06.pdf

From: queries@corec.org.uk
To: dsdd35@hotmail.com
Subject: RE: query
Date: Tue, 13 Feb 2007 07:49:49 +0000

Thank you.
The following reply has been provided by Jo Downing, Information Officer

Thank you for your query. The Research Governance Framework for Health and
Social Care sets out the responsibilities and standards that apply to work managed
within the formal research context.   Under the Governance Arrangements for NHS
Research Ethics Committees (GAfREC), the main role of NHS RECs is to review
research involving NHS patients. GAfREC is available on our website at
www.corec.org.uk/applicants/help/guidance.htm.
Based on the information provided, we consider the study to be service evaluation
and should not be managed as research. Therefore it does not require ethical review
by a NHS Research Ethics Committee or approval from the NHS R&D office.
The attached table sets out the criteria we use to distinguish between research, audit
and service evaluation.
Although ethical review by a NHS REC is not necessary in this case, all types of
study involving human participants should be conducted in accordance with basic
ethical principles such as informed consent and respect for the confidentiality of
participants. When processing identifiable data there are also legal requirements
under the Data Protection Act 2000.
For NHS sites – You should check with the clinical governance office for your
organisation what other review arrangements or sources of advice apply to projects
of this type. You should ensure that the project is not presented as research in the
NHS organisation.
For Universities – You may wish to check whether the project could be reviewed by
the ethics committee within your own institution.
The above advice does not constitute a form of ethical approval but it may be
provided to a journal or other body as evidence that ethical approval is not required
under NHS research governance arrangements.
However, if you feel that ethical review by a NHS REC is essential, please write
setting out your reasons and we will be pleased to consider further.

I hope this helps.

Regards

Queries Line

Central Office for Research Ethics Committees (COREC)
National Patient Safety Agency
Website: www.corec.org.uk <http://www.corec.org.uk>
Ref: 041/01

**

An information leaflet on the New Operational Procedures for NHS Research Ethics
Committees from 1 March 2004 is available at
<http://www.corec.org.uk/applicants/apply/apply.htm#guidance>. Request printed
copies from the COREC office by email to: queries@corec.org.uk
<mailto:queries@corec.org.uk>.

**

This reply may have been sourced in consultation with other members of the COREC
team.
***

From: Sue Ashton [mailto:dsdd35@hotmail.com]
Sent: 12 February 2007 14:36
To: queries@corec.org.uk
Subject: query

With reference to your document CEC E-GROUP July 2006:

I am currently part of a research team to conduct an evaluation of current service
provision of the implementation of the Gold Standards Framework within Care
Homes.

An honorary contract will be in place between the researcher and the care home prior
to interviewing care home managers and disseminating a questionnaire to all care
staff.

Focus groups will be developed for staff and other health professionals e.g GPs

Carers of the residents will be interviewed to establish their experiences of the GSF.

As no patients/ residents are to be interviewed is LREC approval still warranted.

Susan Ashton
Senior Lecturer

Ref 0738

Susan Ashton
Faculty of Health & Social Sciences
Tithebarn Street

Wednesday 1st May 2007

Dear Susan

I am pleased to inform you that the Ethics Committee has considered your application for approval of the project entitled:

An evaluation to determine the impacts of introducing the Gold Standards Framework (GSF), Liverpool Care Pathway (LCP) and preferred Place of Care (PPC) to staff, patients and service users, family caregivers and practitioners involved in the care of older people with dementia in Greater Manchester care homes.

And I am happy to confirm that it has been approved.

The Ethics Committee approval is given on the understanding that:

(i)   any adverse reactions/events which take place during the course of the project will be reported to the Committee immediately;

(ii)   any unforeseen ethics issues arising during the course of the project will be reported to the Committee immediately;

(iii)   any change in the protocol will be reported to the Committee immediately.

Please note that ethical approval is given for a period of five years from the date granted and therefore the expiry date for this project will be April 2012. An application for extension of approval must be submitted if the project continues after this date.

I am enclosing form EC5 and would be grateful if you could spare the time to complete the questionnaire and return it to me.

Yours sincerely,

Jo McWatt
Graduate Research Administrator
Tel: 0151 231 3119
E-mail: j.m.mcwatt@jmu.ac.uk

Encs.

CC: Supervisor

Research and Graduate School Office

Dear

I hope that you do not mind me writing to you at this time.

XXXXXXX, Manager of The XXXXXX Nursing Home has passed on your details and suggested that you might be willing to participate in a research project. I am a researcher from Liverpool John Moores and Edge Hill Universities who is currently undertaking interviews seeking the experience of family members who have taken part in Advance Care Planning on behalf of their relative.

The reason your views and experiences are important to hear about is to improve the quality of care to older people with dementia. The purpose of the research is to find out how relatives, carers and staff experience how the care of older people with dementia is delivered.

Please contact XXXXXX or XXXXXX at the XXXXXX Nursing Home if you need confirmation that this research is genuine.

Your views are very important to us and I hope that you feel able to agree to a short interview. The interview can take place where you feel most comfortable; this could be in your home or in the care home or over the telephone if you prefer. You are also welcome to have someone with you for support during the interview.

If you would like to take part in the research please complete the enclosed form and return it in the self addressed envelope or hand it into XXXXXX. Once I have received the confirmation slip only then will I contact you.

Yours sincerely

Susan Ashton
Researcher / Senior Lecturer Liverpool John Moores University

Name_____

Yes, I would like the opportunity to discuss taking part in the research project which is examining ways of improving the care of older people with dementia in their last years, months, weeks and days of life.

Please contact me by

Telephone / e-mail_____

Preferred
day/time_____

___

My preferred method of Interview would be:

Telephone interview ☐

Face to face interview ☐

Please return in the self addressed envelope provided. I look forward to hearing from you.

Susan Ashton (s.e.ashton@ljmu.ac.uk)
Researcher

PROPOSED INTERVIEW SCHEDULE WITH RELATIVES/ SIGNIFICANT OTHER (2).

The word 'relative' could be substituted depending on the relationship with the resident e.g. husband / wife / partner.

1. Can you tell me about your relative who (prior to their death)was/ is a resident in this care home?

Prompts

1a. Summary of past history of resident and reasons for entering the care home.

1b. Diagnosis and care arrangements of dementia (prior to the admission to the care home)

1c. Length of stay in care home, (prior to the event of death). How did you feel about this?

1d. Description of the deterioration of the resident (up to the event of death if applicable).

1e. Support available / offered prior to admission to care setting or since admission.

2. Describe your experience of the ADVANCE CARE PLANNING process that you have had with the care staff.

Prompts

2a. Written documentation or discussion with the care staff

2b. Did the care staff discuss 'life sustaining treatment' and the role of the GP.

2c. Is it possible to review the document?

2d Involvement in decisions regarding pain control, nutrition and fluids.

2e. Was this a positive experience, how did this help you

2.f What suggestions do you have to improve the process?

2g. To what extent did the care staff try to find out what the view of your relative would have been?

2h. Do you feel that an ACP is necessary?

If applicable.

3 .Can you describe to me the experience and care of the resident in the last few days before they died?

Prompts

3a. Did they die in hospital, if so how was this arranged?

3b. What were you told about your relatives condition? Where you told what to expect?

3c. Was there any part of your relatives care that caused you concern?

3d. Do you know what a care pathway is?

3e. In your view what went well?

3f. Did the care reflect the ACP document?

4. What do you know about the Gold Standards Framework for Care at the End of Life?

(The interviewer may need to summarise the issue if the relative is unfamiliar with the terms)

Prompts

4a. Do you think it is (or would have been) appropriate for your relative with dementia.

4b. Do you think that Care Homes such as this one can cope with the care of the dying resident or do you think hospital is more appropriate.

4c. Has the experience of your relative made you think differently about care homes or care staff?

5. Is there anything else you would like to add.

<u>INTERVIEW</u>

PROJECT TITLE:

Susan Ashton (Researcher) Faculty of Health and Applied Social Sciences

1. I confirm that I have read and understand the information provided for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and that this will not affect my legal rights. ☐

3. I understand that any personal information collected during the study will be anonymised and remain confidential ☐

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

5. I agree to the interview being recorded and to its content being used for research purposes. ☐

Name of Participant	Date	Signature

_____

_____

Name of Researcher	Date	Signature

_____

_____

Name of Person taking consent	Date	Signature
(if different from researcher)		

_____

_____

17 December 2008

Dear

I would like to take this opportunity to thank you for your time and participation in my research project. The interviews were very valuable and I can assure you that confidentiality will be maintained.

Please find attached my business card with contact details should you wish to contact me again.

Yours sincerely

Susan Ashton
Researcher / Senior Lecturer Liverpool John Moores University

Thinking Ahead - Advance Care Planning Discussion

the gold standards **framework** *in care homes*

Advance Care Planning Tool v 1

GSF Advance Care Planning Discussion Paper

We wish to be able to provide the best care possible for all residents and their families, but to do this we need to know more about what is important to them and what are their needs and preferences for the future.

The aim of any discussion about thinking ahead, often called an Advance Care Planning Discussion, is to develop a better understanding and recording of their priorities, needs and preferences and those of their families/carers. This should support planning and provision of care, and enable better planning ahead to best meet these needs. This philosophy of 'hoping for the best but preparing for the worst' enables a more proactive approach, and ensures that it more likely that the right thing happens at the right time.

This example of an Advance Statement should be used as guide, to record what the patient DOES WISH to happen, to inform planning of care. In line with the new Mental Capacity Act, this is different from a legally binding refusal of specific treatments, or what a patient DOES NOT wish to happen, which is called an Advance Decision (sometimes previously called a Living Will).

Ideally an Advance Care Plan should be discussed to inform future care at an early stage, preferably on admission to a home. Due to the sensitivity of some of these issues, some may not wish to answer them all, or may quite rightly wish to review and reconsider their decisions later. This is a 'dynamic' planning document to be adapted and reviewed as needed and is in addition to Advance Directives, Do Not Resuscitate plan, or other legal document.

Patient Name:	Date completed:
Address:	Care Home:
	GP Details
DOB: Hosp / NHS no:	Hospital contact:
Family members involved in Advance Care Planning discussions:	
Name: Contact tel:	
Name of healthcare professional involved in Advance Care Planning discussions:	
Role: Contact tel:	

Patient signature	Date
Next of kin / carer signature (if present)	Date
Care home / Healthcare professional signature	Date
Review date:	

Thinking Ahead - Advance Care Planning Discussion

the gold standards
framework
in care homes

Thinking ahead....

1. At this time in your life what is it that makes you happy or you feel is important to you?

2. What elements of care are important to you and what would you like to happen in future?

3. What would you NOT want to happen? Is there anything that you worry about or fear happening?

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4. *Do you have a Living Will or Legal Advance Decision document?* (**This is in keeping with the new Mental Capacity Act and enables people to make decisions that will be useful if at some future stage they can no longer express their views themselves**) *No / Yes*

If yes please give details (eg who has a copy?)

5. Proxy / next of kin

Who else would you like to be involved if it ever becomes difficult for you to make decisions or if there was an emergency? Do they have official Lasting Power of Attorney (LPoA)?

Contact 1 .... Tel.......................... LPoA Y / N

Contact 2 .... Tel.......................... LPoA Y / N

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6. Preferred place of care

If your condition deteriorates where would you most like to be cared for?

1st choice

2nd choice

Comments

1. Do you have any special requests, preferences, or other comments?

2. Are there any comments or additions from other people you are close to? (please name)

NB See also any separate DNAR/AND or ADRT documents .