

**ADVANCE CARE PLANNING IN
DEMENTIA:
UNDERSTANDING THE PREFERENCES OF PEOPLE WITH
DEMENTIA AND THEIR CARERS**

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Declaration

I, Karen Harrison Dening, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Abstract

The UK End of Life Care Strategy proposed that *all* people should identify preferences for end of life care.

Aims

To explore whether family carers of a person with dementia (PWD) can accurately predict their preferences for end of life care and what factors influence this.

Methods:

This mixed methods study began with nominal groups to explore if PWD and carers could generate and prioritise preferences for end of life care and how much carers influenced the PWD's choices. The second phase involved 60 dyad interviews using a modified Life Support Preferences Questionnaire to assess whether carers of PWD could predict the PWD's preferences for treatment in three health states. The influence of carer burden and distress, and relationship quality, on a carer's ability to predict the PWD's treatment preferences were measured. This was examined further by qualitative interviews to provide personal contexts to decision making.

Results:

In nominal groups, PWD found it difficult to conceive of their future selves and think about preferences for end of life care. Carers' views were influenced by their experiences of caring and negative media coverage of dementia and, when together, carers tended to override the PWD's views. In interviews, carers could predict the PWD's preferences in the here-and-now but were less accurate in future hypothetical health states. PWD and carers showed marked uncertainty about end of life treatment choices. Relationship quality, carer distress and burden had no influence on accuracy of prediction. Qualitative interviews revealed that while dyads claimed to have a shared decision making approach, joint healthcare decision making had largely been untested.

Conclusions:

Families affected by dementia require practical and emotional support at the outset to enable them adapt to changes in usual patterns of decision making, prepare for changes ahead and ensure, where possible, that the PWD's preferences are upheld.

“Even when the experts all agree, they may well be mistaken”

Bertrand Russell (1872 – 1970)

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Terms and Abbreviations

ACP	Advance Care Planning/Plan
ACP-ED	Advance Care Planning in Early Dementia
AD	Advance Directive
ADL	Activities of Daily Living
AN	Admiral Nurse
BAN-S	Bedford Alzheimer nursing severity sub-scale
BEH	Barnet Enfield & Haringey Mental Health Trust
BI	Burden Inventory
BME	Black and Minority Ethnic
BSI	Brief Symptom Inventory
CDR	Clinical Dementia Rating
CFAS	Cognitive Function and Ageing Study
CHF	Congestive Cardiac Failure
CI	Confidence Interval
CMHT	Community Mental Health Team
COPD	Chronic Obstructive Pulmonary Disease
CPR	Cardio Pulmonary Resuscitation
CPFT	Cambridge and Peterborough Foundation NHS Trust
CPN	Community Psychiatric Nurse
CPS	Cognitive Performance Scale
DDSQ	Dementia Diagnostic Screening Questionnaire
DeNDRoN	Dementias & Neurodegenerative Diseases Research Network
DPOA	Durable Power of Attorney
DRG	Diagnosis Related Group
DSM-IV	Diagnostic and statistical manual of mental disorders (4 th edition)
DSM-5	Diagnostic and statistical manual of mental disorders (5 th edition)
EAPC	European Association for Palliative Care
EPA	Enduring Power of Attorney
GDS ¹	Geriatric Depression Scale ¹
GDS ²	Global Deterioration Scale ²
GHQ	General Health Questionnaire
GP	General Practitioner
HCVS: FCI	Health Care Values Survey: Forced Choice Items
HCVSI	Health Care Values Scale Items
HSQ	Health Screening Questionnaire
IADL	Instrument of Activities of Daily Living
ICD10	International Classification of Diseases (10 th Edition)
K10	Kessler Psychological Distress Scale
LCP	Liverpool Care pathway
LPT	Leicestershire Partnership NHS Trust

LSPQ	Life Support Preference Questionnaire
LW	Living Will
MeSH	Medical Subject Headings
MCA	Mental Capacity Act
MCI	Mild Cognitive Impairment
MMSE	Mini Mental State Examination
NART	National Adult Reading Test
NG	Nominal Group
NGT	Nominal Group Technique
NHS	National Health Service
NICE	National Institute for Clinical Excellence
NCI	Neurocognitive Impairment
NCPC	National Council for Palliative Care
NINCDS- ADRDA	National Institute of Neurological and Communicative Disorders and Stroke– Alzheimer’s Disease and Related Disorders Association criteria
NS-SEC	National Statistics Socioeconomic Classification
ONS	Office for National Statistics
OR	Odds ratio
PABAK	Prevalence and Bias Adjusted Kappa
PCC	Person Centred Care
PSDA	Patient Self Determination Act
PWD	Person with dementia
QCPR	Quality of Carer Patient Relationship
R&D	Research & Development
RCT	Randomised Control Trial
REC	Research Ethics Committee
RS	Response Shift theory
SCB	Screen for Caregiver Burden
SCIE	Social Care Institute for Excellence
SD	Standard Deviation
SOC 2010	Standard Occupational Classification 2010
SPSS	Statistical Package for the Social Sciences
TICS	Telephone Interview for Cognitive Status
UCL	University College London
UK	United Kingdom
USA	United States of America
WLMHT	West London Mental Health Trust
WHO	World Health Organisation
VPS	Values Preference Scale
ZBI	Zarit Burden Interview

CHAPTER 1

INTRODUCTION

1.1 Scope of the thesis

My thesis describes work I conducted during a part time research doctorate undertaken between 2008 and 2014, exploring the preferences for end of life care of people with dementia (PWD) and their family carers¹ in influencing the initiation and process of advance care planning. I will first set the scene before going on to describe the background to my field of study.

Chapter one comprises the background and context to the study firstly discussing how, as an Community Psychiatric Nurse, I came to study this subject area. I will then consider the syndrome of dementia and its context within the population. This is essential in understanding the implications of its diagnosis, trajectory and end of life care elements of the disease. I will consider the implications of relevant epidemiological aspects of an ageing population. I will discuss the term *dementia*; however this thesis will not enter into discussion of the subtypes, clinical features and diagnostic criteria of dementia. Dementia is a life-limiting illness, but the relevance and impact of other co-morbid conditions are also important in considering what it is to die from and with dementia. I will then set the policy context to palliative and end of life care for PWD and their family carers.

Chapter two presents a detailed review of the literature relating to advance care planning in dementia; I undertook this as preparatory work to identify the current evidence base for advance care planning specifically in dementia. As this was a part-time doctorate the initial review was completed very early on in the study, so in preparation of the thesis, I updated the review to include relevant literature that had

¹ A carer is defined as someone who 'spends a significant proportion of their life providing unpaid support to family or potentially friends. In this thesis the term 'carer' is, on occasion, substituted with that of 'caregiver' - a term which has the same meaning. In order to reduce potential confusion between the concepts of 'caring about' and 'caring for' the terms 'caring' and 'caregiving' will both be used at times to convey the meaning of providing care.

emerged in the ensuing period. The review thus includes a published paper on phase one of this doctoral study, of which, further detail is to be found in chapter three.

In **Chapter three**, I present the nominal group study undertaken, very much as preparatory work for the main study phase. In this part of my research I wanted to understand if PWD and their family carers were each able to express preferences for end of life care in the context of advance care planning. **Chapter four** presents and discusses the methods employed for cross-sectional interviews of dyads (PWD and their family carers) to form the main basis of this thesis. In **Chapter five** I present the findings of the cross sectional interviews and discuss these. In **chapter six** I describe a nested, qualitative semi-structured interview study that contextualised the cross sectional interviews; the findings are presented and discussed. I discuss each chapter in turn but, finally, in **chapter seven**, I bring the main research findings together to present the conclusions to the entire study.

1.2 Researcher perspective and Admiral Nursing

I come to this research as a nurse with over thirty five years' experience, trained in mental health, learning disabilities and general nursing. I elected to work with older people with mental health problems in the early 1980s, as the specialism of old age psychiatry was being established across the United Kingdom (UK). Personal experience and reflective practice informed me that to be effective in caring for older people with mental health problems, a general nurse qualification was essential as many patients had co-morbid physical health conditions as well as psychiatric conditions. As my nursing career progressed I became more interested in dementia care, taking a post in an acute assessment ward and later in a community setting supporting families of PWD as a community psychiatric nurse (CPN). In my first position as a CPN staff nurse, a case allocated early on was that of an elderly couple where the wife had a diagnosis of mild to moderate Alzheimer's disease (Figure 1.1).

I reflected upon this case for many years afterwards and how I might better support PWD to understand their needs and involve them in planning care for the future. As my practice in the field of dementia care evolved I came to understand that the service I offered to patients had to be sensitive to the context of the family relationship within which they existed. Supporting current and future care planning could not occur in isolation from the family as a whole.

Figure 1.1 Case study

During my first year as a Community Mental Health Nurse, I was allocated a person with mild to moderate dementia whose husband had consulted the GP raising concerns that she was also depressed. Her husband was her main carer at home but had very advanced chronic obstructive pulmonary disease (COPD). The GP sought the involvement of the Community Mental Health Team (CMHT) to assess her for depression. Following a comprehensive assessment both at home and in a day hospital setting it was agreed that she was not depressed but that her husband was experiencing marked carer stress on top of significant failing health. Over a weekend he took himself and his wife into their car in the garage with a suicide plan. She died of carbon monoxide poisoning but he survived, claiming to have fallen onto the door handle and rolling out. He was not charged with any offence but then remained under the care of the CMHT for assessment of his own mental health. He divulged that he felt his wife's life was meaningless with dementia and stated that he would also take his life when he felt his COPD rendered his life meaningless. We discussed his need for control and how he could document his wishes for the future using a Living Will, available through the Terrence Higgins Trust² at the time. He completed this over a few months. He eventually died of natural causes but with a sense of control towards the end. Whilst this was a very distressing case to hold as a junior nurse the experience has developed in me a keen interest in advance care planning.

² <http://www.tht.org.uk/myhiv/Your-rights/Ageing/Advance-decisions>

In April 2007 I became an Admiral Nurse (AN), initially as a consultant nurse, followed by a wider role as the lead practice development nurse for all Admiral Nurses and, more recently as Director of Admiral Nursing.

1.3 Admiral Nursing

Admiral Nursing (AN) was first piloted in 1991 as a result of one family's negative experiences of caring for their father who had vascular dementia. Admiral Nurses (ANs) are the only group of qualified nurses in the UK who focus on working with families affected by dementia. They are principally mental health nurses who, alongside other health and social care professionals, work with families, both the person with the diagnosis and their family carers, in order to help them to live positively, develop and maintain skills for coping and communication, and maintain relationships (Bunn et al., 2013; Harrison Dening, 2010). As of the end of 2013, there were just over 125 Admiral Nurses in England, located in the following areas: London, Kent, Hertfordshire, Southampton, Yorkshire, the West Midlands, the North West and North East of England. Admiral Nurses are hosted and funded in NHS and social care trusts, not for profit organisations and care homes, however funding for such posts varies dependent upon the employing organisation. The charity Dementia UK provides a central organisational structure to support their work (www.dementiauk.org).

The evidence base for Admiral Nursing is limited. One quasi-experimental study was undertaken over ten years ago when Admiral Nursing was still in its developmental stages (Woods, 2003). This was a design using the General Health Questionnaire (GHQ) as an outcome measure for 104 family members in receipt of admiral nursing (n = 43) compared with regular CMHT involvement (n = 61). Over an 8 month period better outcomes were seen for anxiety and insomnia in the AN

intervention group over usual care ($P=0.038$). The authors acknowledged a number of limitations to this study, including methodological challenges arising from differences in the population seeking AN intervention, such as randomisation and the need for a longer follow up period (Woods, 2003).

Only two other peer reviewed studies have been published about the role of AN. One of these used semi-structured interviews in 16 case studies to explore the decision making processes ANs engage in (Burton, 2005). The study demonstrated a high complexity of cases, with the decision to offer a service to carers influenced not only by perceived need, but also upon the nurses feeling professionally responsible for perceived gaps in service provision. The second is a series of qualitative case studies which illustrates the practice of the AN through individual case studies (Keady et al., 2007). The remaining literature concerning ANs has been published in non peer-reviewed professional journals.

The focus of this study, however, is not the role of the AN per se but the emerging call for health and social care practitioners, such as ANs, to support PWD and their families in the process of advance care planning.

Before starting this research study, I had become increasingly interested in the role and function of ANs in palliative and end of life care in dementia (Harrison Dening, 2010) and more specifically their role in advance care planning. From my early experiences as a CPN (Figure 1.1) supporting older people with mental health problems and co-morbid conditions to develop living wills, I became conscious that enabling the future wishes of a person with dementia to be enacted was inextricably linked with the support of their families. From there I had a growing enthusiasm to conduct research exploring how families affected by dementia might approach advance care planning and the role of the AN in supporting it.

1.4 An ageing population

People aged 60 years and over make up the most rapidly expanding segment of the population. Between 2000 and 2050, the proportion of the world's population aged over 60 years old will more than treble from 605 million to 2 billion (WHO, 2012). Not only are more people surviving into old age, but also tending to live longer in old age. Over the next 50 years global life expectancy at age 60 is expected to increase from 18.8 years in 2000-2005 to 22.2 years in 2050 (WHO, 2012). In the UK alone, the percentage of older people (aged 65 years and over) increased from 13% of the total population in 1971 to 16% in 2005 (ONS, 2005). The numbers of those reaching the oldest ages are increasing the fastest: in 2008 there were 1.3 million people in the UK aged 85 and over, with this expected to increase to 1.8 million by 2018 and to 3.3 million by 2033 (ONS, 2013). These changes to the age structure of the population will influence both the prevalence and incidence of age-related conditions such as dementia (Stephan and Brayne, 2008).

1.5 Dementia

1.5.1 Dementia: a definition

The word *dementia* is taken from the Latin *demens*, originally meaning 'madness', from *de-* 'away from' + *ment*, the root of *mens* 'mind' which translates literally as '*away from your mind*'. The first reference to its common usage was in Blancard's Physical Dictionary in 1726. There, it was defined as '*the extinction of the imagination and judgement*' (Berrios, 1996). The term dementia was incorporated into the European common parlance in the 17th and 18th centuries (Berrios, 1996). A modern dictionary definition of dementia would be of '*a chronic or persistent disorder of the mental processes due to brain disease or injury*' (OUP, 2011). There

are many slightly different medical definitions of dementia; the National Dementia Strategy (DH, 2009), defined dementia as:

“.. a syndrome which may be caused by a number of illnesses in which there is progressive decline in multiple areas of functioning, including decline in memory, reasoning, communication skills and the ability to carry out daily activities. Alongside this decline, individuals may develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering, which cause problems in themselves, which complicate care, and which can occur at any stage of the illness”. (p 15)

This thesis will not give any further consideration to the historical account of dementia, other than recognising that it has been the subject of much description, philosophical and academic debate and study for many centuries, and will join this debate in the present century.

1.5.2 Dementia: a syndrome

Dementia traditionally is a term used to describe a syndrome; a collection of symptoms, including a decline in memory, reasoning and communication skills, and a gradual loss of skills needed to carry out daily living activities. These symptoms are caused by structural and chemical changes within the brain as a result of neurodegenerative changes. The cognitive changes arising in dementia are determined to a large extent by the areas of the brain that are affected by the underlying pathological processes. These processes include tissue destruction, compression, inflammation, and biochemical imbalances. In other words, the process of dementia is the end stage manifestation of numerous brain disorders (Piggot and Court, 2008; Wilcock et al., 1999; Fratiglioni and Qiu, 2013). Dementia, therefore, is not a disease in itself but a syndrome: a collection of

neuropsychological deficits that have occurred as a result of chronic brain disease (Nuffield Council on Bioethics, 2009; Fratiglioni and Qiu, 2013). This syndrome may result from Alzheimer's disease, cerebral vascular disease, and in other conditions primarily or secondarily affecting the brain.

The American Psychiatric Association's DSM-5 task force developed revisions of DSM-IV (American Psychiatric Association, 1994), including those of dementia. It was argued that scientific advancement and changing views in clinical practice were drivers for a review of the current terms used (Ganguli et al., 2012). The terms of Major and Minor Neurocognitive Disorder are terms now assigned to dementia within DSM-5, under the broader heading of Neurocognitive impairment (NCI). The term *dementia* is still used within DSM-5 in aetiological subtypes (American Psychiatric Association, 2013).

For the purposes of this study the term dementia will be used in its broadest and most inclusive sense and any reference to dementia will be in relation to the ICD-10 classification manual (WHO, 1992).

“Dementia is a syndrome due to disease of the brain, usually of a chronic nature, in which there is a disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. Impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour or motivation.

(The primary requirement for diagnosis is evidence of decline in both memory and thinking which is sufficient to impair personal activities of daily living...The above symptoms and impairments should have been evident for

at least six months for a confident diagnosis of dementia to be made)." (p 45)

The ICD-10 definition and description of dementia above espouses the bio-medical approach to understanding dementia characterised by biological changes and a set of symptoms by which to define the experience of dementia.

1.5.3 The prevalence of dementia

It is estimated that there are currently 44.4 million people worldwide with dementia, and (if mortality, prevention and treatment remain the same) this number will increase to an estimated 75.6 million in 2030, and 135.5 million in 2050 (ADI, 2013). Ferri et al. (2005) conducted a Delphi consensus study, which aimed to provide dementia estimates separately for each world region. Twelve international experts were provided with a systematic review of the available data and asked to calculate prevalence estimates for each five-year age band in 14 regions, based on a combination of geography and patterns of mortality. The group response for each region was then summarised as a 'mean prevalence estimate'. According to their findings, over 24 million people had dementia worldwide and they predicted that this was likely to double every 20 years to over 81 million in 2040. Stephan and Brayne (2008) indicate that age-specific estimates of dementia are consistent worldwide with a predicted exponential rise in dementia with age.

In the UK it has been estimated that as many as 25 million people (42% of the UK population) will know a close friend or family member affected by dementia (Luengo-Fernandez et al., 2010). Exact figures for PWD are hard to obtain but the Dementia 2014 Report (Alzheimer's Society 2014) estimates that the number of people in the UK with dementia (both diagnosed and undiagnosed) is currently around 835,000. This figure equates to 1.3% of the entire UK population. Though

these statistics have recently been challenged (Matthews et al., 2013; Norton et al., 2013) we know that increasing age appears to be the strongest risk factor for developing dementia (O'Connor, 2010; Paykel et al., 1994) and that these numbers are forecast to rise.

1.5.4 Dementia: The medical paradigm

Professional and academic explanations of dementia fall broadly between the medical and psychosocial models. The authors of the NICE/SCIE Dementia Guideline (National Collaborating Centre for Mental Health, 2006) refer to two different and potentially polarised approaches to dementia. The first of these is the clinical (medical) perspective where dementia is viewed as 'a group of usually progressive neurodegenerative brain disorders characterised by intellectual deterioration and more or less gradual erosion of mental and later physical function, leading to disability and death' (National Collaborating Centre for Mental Health, 2006). In contrast to this is the 'social perspective' in which dementia is cast as one of numerous causes of changes in a person's capacities, and is only experienced as disabling when there is a lack of appropriate environmental support.

The clinical approach systematically defines the characteristics of dementia and places them within a medical context, under neurodegenerative diseases and the lesions and deficits associated. Increasing interest in the pathology and cellular mechanisms in dementia and the realisation of different patterns, e.g. in Alzheimer's and vascular disease, led to the development of more precise diagnostic criteria (e.g. McKhann et al., 1984) which then became incorporated into the ICD-10 (WHO, 1992) and Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (American Psychiatric Association, 1994).

Thus dementia became medical territory, and is generally assigned to the broad domain of mental illness. However, a recent and important challenge to dementia's inclusion within the paradigm of mental illness was made by the Nuffield Bioethics report on dementia (2009) in their formal statement that dementia arises as a result of brain damage. It therefore questions the categorisation of dementia entirely as a mental illness as it can also be regarded from a more neurological perspective.

1.5.5 Dementia and multimorbidity

As dementia is largely a disease of old age, many PWD will also have other co-morbid illnesses or disabilities. In medicine, co-morbidity is defined as one or more coexisting medical conditions or disease processes that are additional to an initial diagnosis (Mosby, 2008), however the term multimorbidity is now the widely accepted term. While there are varying definitions in the medical literature, multimorbidity is defined as the co-existence of two or more chronic conditions, where one is not necessarily more central than the others (van den Akker et al., 1996; Boyd and Fortin, 2010). Multimorbidity correlates with age and represents the most common 'disease pattern' found among the elderly. Multimorbidity is characterised by complex interactions of co-existing diseases where a medical approach focused on a single disease does not suffice. People with dementia and cognitive impairment show high levels of multimorbidity (Cigolle et al., 2007; Doraiswamy et al., 2002), common conditions including cardiovascular disease, diabetes, and musculoskeletal disorders such as fractures.

Many studies have investigated the relationship between multimorbid conditions and dementia: prevalence and incidence; numbers of concurrent multimorbid conditions; and specific multimorbidities common in dementia such as under nutrition and weight loss, urinary tract infections and incontinence, pain, heart disease, etc (Ahluwalia et al., 2011; Cigolle et al., 2007; Cronin-Stubbs et al., 1997; Doraiswamy

et al., 2002; Eriksson et al., 2009; Feldt et al., 1998; Prince et al., 2011; Tschanz et al., 2004; Zuliani et al., 2011). Tschanz et al. (2004) found that multimorbid medical conditions were positive predictors of mortality in dementia, although dementia itself was the strongest predictor of mortality, with the risk being two to three times greater than those of other life-shortening illnesses. However, through the pressure for diagnosis in policy and the Prime Ministers Challenge, dementia has become the index condition which thus diagnostically overshadows all other conditions experienced by the individual (Iliffe 2013).

Multiple multimorbid conditions not only have a cumulative effect but also interact to have a multiplicative impact. Marengoni et al. (2011), in a systematic review of 41 papers, found the major consequences of multimorbidity were disability and functional decline, poor quality of life, and high health care costs. René et al. (2013) conducted a population-based cohort study, following 310 PWD longitudinally. They compared their trajectories with those of 679 people without dementia and found that multimorbidity was related to accelerated decline in PWD but not in non-demented individuals.

Moreover, PWD are more likely to experience under assessment and under treatment of any multimorbid condition than people with other long term conditions (Davies and Higginson, 2004). Families affected by dementia often present their concerns and problems to the ANs in respect of other multimorbid illnesses, such as diabetes or cancer.

These illnesses and conditions are in addition to the dementia and often present the carer with, for example, practical problems in following treatment regimes or in understanding prognosis. It is often when a multimorbid condition threatens the life of the person with dementia that carers find decision making especially difficult and

such events can expose how they may not fully understand the life limiting nature of dementia.

1.5.6 Dementia: A life limiting condition

Life expectancy is increasing at a faster rate than healthy life expectancy (Froggatt, 2006) so people often develop a range of conditions and disabilities in the years of old age before death. The greatest users of the health and social care system are frail older people with multiple conditions, and is strongly associated with cognitive impairment (Kulmala, 2014). Despite the impact that dementia and frailty have on older people and their families, they have not traditionally been conceptualised as 'terminal' or 'life limiting' syndromes (Sampson and Harrison Denning, 2013). In one study of nursing home carers and physicians, at nursing home admission only 1.1% of residents were perceived to have life expectancy of less than 6 months however, 71% died within that period (Mitchell et al., 2004). Acute physical illness requiring emergency hospital admission, such as pneumonia or urinary tract infection, may be an indicator of imminent death in people with advanced dementia (Mitchell et al., 2009; Morrison and Siu, 2000; Sampson et al., 2009).

Dementia is a progressive, irreversible neurodegenerative condition, (Neale et al., 2001; Wilcock et al., 2008; Xie et al., 2008), and once it is diagnosed people will die with dementia regardless of the primary cause of death (Wilcock et al., 2008). Although dementia has been identified as one of the leading causes of death (Foley and Carver, 2001), exact numbers of deaths where dementia is a primary or secondary cause remain uncertain (Harris et al., 2010). This is thought to be due to under-reporting of dementia on death certificates (Morgan and Clarke, 1995; Martyn and Pippard, 1998). However, Xie et al. (2008), from analysis of a longitudinal population based cohort study, report a median survival time from symptom onset of

dementia to death was 4.5 years and concluding that one in three people (30%) will die with or from dementia. Similarly, Rait et al. (2010) found that the median survival time from the diagnosis of dementia was 3.5 years. Despite UK estimates that approximately 100, 000 PWD die each year (Bayer, 2006), Martyn & Pippard (1998) reported that fewer than 25% of people diagnosed with dementia during their life had their diagnosis recorded as an underlying cause of death on the death certificate.

Whilst many PWD die of a medical complication, such as pneumonia or another infection, dementia itself can be the cause death; for example, general wasting, malnutrition, and dehydration are real risks when a person with dementia can no longer eat safely and move independently. However, the stigma of the disease and the lack of recognition that dementia is a life limiting illness have led to neglect in addressing the end of life challenges for PWD and their carers (Sampson et al., 2006).

1.6 Dementia and palliative care

To understand the UK policy drivers for better care for older people and PWD approaching the end of their lives, it is worth first exploring how the terms 'palliative care' and 'end of life care' have been defined and used.

Palliative care (from Latin *palliare*, to cloak) is a form of specialised medical or social care for people with serious illnesses. It is focused on providing relief from the symptoms, pain, and stress of a serious illness, whatever the diagnosis. It may apply to patients in all disease stages, including those undergoing treatment for curable illnesses and those living with chronic diseases that are ultimately life-limiting, as well as patients who are nearing the end of life.

The World Health Organisation (2011) define palliative care as:

'Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'.

In recent years there has been a significant increase in policy and guidance, across many countries, which directly influences and promotes palliative and end of life care for non-malignant life limiting conditions. In the UK the provision of palliative care services, irrespective of diagnosis or age, has been supported by a number of government reports (Table 1.1).

It was not until 1998 that the National Council for Hospice and Specialist Palliative Care Services (now known as the National Council for Palliative Care, NCPC), proposed the need to extend palliative and hospice care services, which had developed originally in cancer care, to all people with non-malignant disease (Addington-Hall et al., 1998). It was over a decade that their guidance specifically for PWD came out (NCPC, 2009).

Using data from a retrospective population-based survey of 3,696 deaths (Addington-Hall and McCarthy, 1995a; 1995b) a secondary analysis was carried out to investigate people's experience of dying from causes other than cancer (Addington-Hall, 1998). The results suggested that 16.8% of people with non-malignant disease and their families were as much in need of specialist palliative care services as those with cancer, specifically in promoting autonomy for patients (Addington-Hall, 1998).

In 2001 a call was made for equitable access to palliative and end of life care for older people in the National Service Framework for Older People (DH, 2001). The document set eight standards for improving the health and social care of older people, which aimed the first of the eight standards, to ensure that older people are never unfairly discriminated against in accessing NHS or social care services as a result of their age:

Standard One: Rooting out age discrimination

“NHS services will be provided, regardless of age, on the basis of clinical need alone. Social care services will not use age in their eligibility criteria or policies, to restrict access to available services”.

Many older people and their carers reported that palliative care services had not been available to them (Cleary and Carbonne, 1997). This was doubtless due to the fact that palliative care services had been concentrated on those with cancer and specialist needs. In 2003 a national consultation was carried out to explore how equity in access to palliative care services could be progressed which resulted in the publication of *‘Building on the Best’* (DH, 2003).

This was closely followed by the World Health Organisation (WHO), *‘Better Palliative Care for Older People’* (Davies and Higginson, 2004), which focused on the special needs of older people and the rising demographic challenges posed for health care systems. The WHO then updated the earlier document with *‘Palliative Care for Older People: Better Practices’* (WHO, 2004) which, whilst reiterating the concerns made in the earlier publication (Davies and Higginson, 2004), emphasised the importance of joint working across health and social care to improve palliative care for older people. However, staff carrying out palliative care fall into two categories: generalists and specialists and as an individuals’ palliative care needs

will vary in complexity (Burt et al., 2005). Quill et al., (2013) argue that many elements of palliative care can be provided by existing specialist or generalist clinicians regardless of discipline but, central to this is in recognising when a person has palliative care needs and this has been of central concern in end of life care for PWD.

Following several years of policy and guidance indicating the need for improved access to palliative care services for older people at the end of life it was a natural next step to call for fair access to palliative and end of life care for PWD.

At the time when the joint *National Institute for Clinical Excellence (NICE) / Social Care Institute for Excellence (SCIE) guideline for dementia* (NCCMH, 2006) was being developed there was scant research evidence for palliative and end of life care for PWD, so a group of experts (myself included) made nine recommendations based on consensus agreement of best practice. Equitable access to palliative care services for people affected by dementia was a specific recommendation, and

another was that advance directives³ should be considered (discussed further in section 1.9).

The inclusion of dementia in palliative and end of life policy and guidance has resulted from several contributory factors, especially:

- (i) Increasing numbers of PWD;
- (ii) Concerns about inappropriate interventions and treatments at the end of life; and

³ Advance Care Planning is an umbrella term that encompasses advance directives, living wills, advance statements (Henry and Seymour, 2007).

Table 1.1 Policy: Dementia, palliative and end of life care

Publishing body	Year	Report
Department of Health	2001	National Service Framework (NSF) for Older people
	2003	Building on the Best
	2008	End of Life Care Strategy
	2009	Living Well with Dementia: A National Dementia Strategy
	2010	Quality outcomes for people with dementia: Building on the work of the national dementia strategy
	2011	Prime Minister's Challenge on Dementia
National Institute for Clinical Excellence & Social Care Institute for Excellence	2006	NICE/SCIE guidelines for dementia
	2012	End of life care for people with Dementia: Commissioning guide
World Health Organisation	2004	Better Palliative Care for Older People
	2004	Palliative Care for Older People: Better Practices
Care Services Improvement Partnership	2005	Everybody's business – Integrated Mental health Services for Older Adults: a service development guide
Audit Commission	2000	Forget Me Not; Developing Mental Health Services for Older People in England
	2002 (revision)	
National Audit Office	2007	Improving services and support for people with dementia
	2008	End of life
	2010	Improving Dementia Services in England – an Interim Report
Alzheimer's Society	2007	Dementia UK
European Association for Palliative Care (EAPC)	2013	White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the EAPC
National Council for Palliative Care (NCPC)	2009	Out of the Shadows

- (i) Discrimination against PWD that limits their access to palliative care services.

(Lloyd-Williams and Payne, 2002).

The body of accumulating policy and research evidence has helped to drive this agenda forward.

1.6.2 Policy developments in advance care planning

The End of Life Care Strategy (DH, 2008) and the National Dementia Strategy (DH, 2009) both have significant potential for improving palliative and end of life care for PWD. The End of Life Care Strategy (DH, 2008) stated that *all* people should identify their needs, priorities and preferences [advance care planning] for end of life care, document and review them and that these should be respected and acted upon wherever possible.

The National Dementia Strategy (DH, 2009) details a five year plan to radically transform the quality of care for PWD and their carers'. The government pledged an additional £150 million investment over the first two years, to support local services in implementing the plan. The strategy, due to be updated in 2014, has three key themes:

- i. To improve awareness of dementia, among both the public and professionals.*
- ii. To promote early and accurate diagnosis and intervention.*
- iii. To deliver high quality care and support for people with dementia and their carers*

These themes are addressed through 17 objectives. Particularly pertinent to this study is the twelfth objective (p: 61):

Objective 12: Improved end of life care for people with dementia.

“People with dementia and their carers to be involved in planning end of life care which recognises the principles outlined in the Department of Health End of Life Care Strategy. Local work on the End of Life Care Strategy to consider dementia”.

Within its stated ‘case for change’, the dementia strategy strongly emphasises the need to link any service development in end of life care for PWD to the Department’s End of Life Strategy (DH, 2008).

“In dementia, end of life planning needs to take place early, while someone has sufficient mental capacity and where decisions and preferences can be recorded consistent with the principles set out in the Mental Capacity Act. This could include the use of lasting powers of attorney, advance decisions and advance statements”.

The Dementia Strategy was followed, three years later, by the UK Prime Minister declaring dementia a ‘National Priority’ for health and social services (DH, 2012b), with a commitment to continue to drive hard the agenda for change and reform. However, the main areas for attention were raising awareness, earlier diagnosis and care in acute hospitals. There have been several terms used in connection to the diagnosis of dementia; early, timely and screening. There has been much debate in the medical profession on the issue of screening for dementia. Fox et al. (2013) presented a laudable debate on this arguing the poor evidence base for screening and the potential for harm in making many false positive diagnoses. Early diagnosis of dementia has been a concern of researchers for some time with pressure to look

for biomedical profiles or biomarkers, which assume a very close link between the patho-biology long before the manifestation of the clinical syndrome (Fox et al. 2013). Whilst early diagnosis and screening will not be explored further in this thesis, a timely diagnosis of dementia may be pertinent when considering a person's ability to engage in advance care planning. Dedhi et al. (2014) argue that timeliness in the diagnosis of dementia involves a GP balancing a range of judgements including such things as when to undertake certain tests and measures, when to discuss with the person and their family, the context and any possible treatments or services available thereafter. However, a timely diagnosis in the context of advance care planning would be that the person with dementia is in receipt of their diagnosis at such a timely point whereby they still have capacity to make plans for their future. However, the Prime Minister's Challenge (2012) made no further mention about end of life care nor, indeed, of advance care planning.

Dementia is clearly a high priority not just within the UK but all other major countries, evidenced by the recent G8 summit focusing on a global call to action on dementia (G8, 2013). No specific mention was made to end of life care for PWD, but generally to build upon research collaborations across the member countries to strengthen efforts to better meet the challenges that dementia presents society.

Recently, van der Steen et al. (2013) used a Delphi consensus process involving 64 experts from 23 European countries, including the UK, to provide the first definition of palliative care in dementia. Fifty seven recommendations were made covering eleven domains, with the aim of providing guidance for clinical practice, policy and research. For the purposes of this thesis attention is drawn to domain three:

Domain 3. Setting care goals and advance planning

- 3.1 *Prioritising of explicit global care goals helps guide care and evaluate its appropriateness.*
- 3.2 *Anticipating progression of the disease, advance care planning is proactive. This implies it should start as soon as the diagnosis is made, when the patient can still be actively involved and patient preferences, values, needs and beliefs can be elicited.*
- 3.3 *Formats of advance care plans may vary in terms of preferences, the amount of detail required, and what is available in the specific setting for the individual.,*
- 3.4 *In mild dementia, people need support in planning for the future.*
- 3.5 *In more severe dementia and when death approaches, the patient's best interest may be increasingly served with a primary goal of maximisation of comfort.*
- 3.6 *Advance care planning is a process, and plans should be revisited with patient and family on a regular basis and following any significant change in health condition.*
- 3.7 *Care plans should be documented and stored in a way that permits access to all disciplines involved in any stage and through transfers.*

(van der Steen et al., 2013)

Despite the limited focus on ACP in dementia in UK policy and guidance, the EAPC White paper presents a significant milestone to support its development. It is an area of great interest to Admiral nursing: translating this policy and guidance into

nursing and multidisciplinary practice to support people affected by dementia and their families to plan ahead for future care and the end of life.

1.7 Personhood: an alternative paradigm

The medical paradigm of dementia as a 'disease' was challenged from the early 1980s through the work of Tom Kitwood and his colleagues at the Bradford Dementia Group. They conceptualised an alternative approach for the *social* understanding of PWD. Rather than the medical view of lesions and deficits affecting cognitive function, they sought to encourage us to consider a person's attributes and strengths. Kitwood published many articles during the 1980's and 1990's, bringing these ideas together in his seminal work, *Dementia Reconsidered: The Person Comes First* (Kitwood, 1997). Person centred care (PCC) is now a widely acknowledged, holistic basis for care delivery, incorporating biology and neurology but also refers to treating people as individuals, respecting their rights as a person and (from a professional carer perspective) building therapeutic relationships (McCormack and McCance, 2010).

There has been much philosophical debate over centuries as to what it is to be a 'person', with debate that considers both our humanity and individuality (Frankfurt, 1989; Jolley, 1999). Frankfurt goes on to state that being a person is not a question of biology alone, but also a question of other attributes.

'Personhood' is a central idea in person-centred care. Kitwood (1997, p. 8) defines it as "a standing or a status that is bestowed on one human being, by another in the context of relationship and social being". In addition, Kitwood sees personhood as transcendent, sacred, and unique; and that it accords people who have dementia with an ethical status that offers them absolute value. Biomedical ethics does not

specifically address the subject of personhood or non-personhood but appears to prefer to use terms such as competency and non competency (Beauchamp and Childress, 2013). Implicit within this however, is that competency equals personhood and non competency equals non-personhood. Kitwood (1997) argues the primary stance that each *person* (with dementia) has absolute value over and above that of the disease, and he framed what it is to have dementia thus:

Figure 1.2 On being a person with dementia

The **PERSON** with dementia
(as opposed to)
The person with **DEMENTIA**

(Kitwood, 1997, p 7)

Person centred care is one of the main theoretical approaches that underpins Admiral Nurses' practice in their work with families affected by dementia. However, experience indicates that adopting a solely person centred approach for the person with dementia may be in conflict with the perspectives of a family carer and vice versa. Therefore the focus of Admiral Nursing should be more appropriately on relationship centred care, including the whole family, where the interests of each are explored.

1.7.1 The attributes of personhood

Several philosophers have sought to determine the attributes of what it is to be a 'person' and what distinguishes 'personhood' in human beings as opposed to other

species (Frankfurt, 1989; Kitwood, 1997; Quinton, 1973). The attributes of a 'person' are suggested to have both physical and psychological components.

In Western society, we tend to regard cognitive attributes as being of the highest order (Post, 2006). However, does this therefore mean that if we lose one or more of these cognitive abilities, we are diminished or even risk losing our status as a person?

Kitwood, when considering the person with dementia in the debate on person and personhood, argued that the state of personhood is a status that is bestowed upon one human being by another and thus is centred within the context of social being (Kitwood, 1997). This implies that personhood is an outcome of a relationship between two or more people and relies on the action of the bestowal of one to another, with, in this instance, the person with dementia being the passive recipient.

It should be borne in mind, however, that Kitwood's work mainly involved PWD in institutional settings and the relationships of family carers were not his primary focus. Nolan *et al* have argued that this basis for person centred care fails to capture the interdependencies and reciprocities that underpin caring relationships, especially across those of family members (Nolan et al., 2002). The impact of relationships in dementia care is a relatively unexplored area (Smebye and Kirkevold, 2013; Lawrence et al., 1998; Snyder, 2000).

However, we also need to consider the impact of a diagnosis of dementia for remaining family members. People with dementia are often referred to as 'already dead' (Gubrium, 1986; Herskovits 1995) while they are quite obviously physically alive. Post (2006) discusses how PWD are often seen as 'nonpersons' due to their failing capacities. In my own practice, I see how these issues contribute to the

anxieties that carers have about, not only what the future might hold for the person with the diagnosis, but also their own future health. A question often raised is 'will I get dementia too?' Raising awareness about dementia is a double-edged sword and whilst it may reduce stigma, it may also raise concerns of the possibility of developing dementia. In a recent poll, those over the age of 55 feared dementia (58%) more than any other condition, including cancer (47%) (Alzheimer Research Trust, 2010). This is often keenly felt by families of a person with dementia.

1.8 Autonomy and decision making in dementia

In this next section I will examine decision making in the context of preferences for end of life care in dementia. I will briefly consider the philosophical concept of autonomy in relation to capacity and competence in making decisions and how dementia is perceived therein. I will also discuss the Mental Capacity Act 2005, measures to support decision making in dementia and then family or proxy⁴ decision making on behalf of PWD.

1.8.1 Autonomy and dementia

Autonomy is an important concept in relation to the philosophy of the self and with regard to decision making. A dictionary definition of autonomy is *the ability of the person to make his or her own decisions* [in a medical context] (OUP, 2011). The German philosopher Kant argued that autonomy is demonstrated by *one who is able to decide on a course of action* (Walker and Meredith, 2008). But, does this mean being an active agent as many people may be able to decide on a course of action and yet not be autonomous? Respect for a patient's personal autonomy is considered one of many fundamental ethical principles in medicine, and

⁴ A surrogate decision-maker, also known as a health care proxy or agent, is an advocate for an incompetent patient who speaks for the patient. For the purposes of this study I will use the term proxy to mean a family or person close to the person with dementia who is making decisions on their behalf.

autonomy is the central premise of the concept of informed consent (Beauchamp and Childress, 2013).

Locke (Jolley, 1999) adds the dimension of time to the argument and states that autonomy and personal identity depend upon consciousness: that is to say, we are conscious of our past and *future* thoughts and actions in the same way as we are conscious of our present thoughts and actions. Dementia would confound this perspective on autonomy because, as dementia progresses, the ability to consider future thoughts and actions becomes compromised, thus affecting decision making abilities (Fratiglioni and Qiu, 2013). However, because PWD have a lifetime's experience of making decisions for themselves before the onset of the disease, so family carers are often assumed to know what any such decisions would had they not lost capacity (Wendler and Rid, 2011). Thus carers find themselves increasingly in a position whereby they are called upon to inform, or directly make, decisions on behalf of the person with dementia.

Wishes and preferences for future care are assumed to be based upon the principles of autonomy, whereby a person expects to retain personal control in making decisions. However, there is often a desire in older adults to consider family ties and the collective process of family decision may be of equal importance (Whitlatch et al., 2009; Roberto, 1999). Friedman et al. (2002) proposed that the individualistic sense or value of autonomy becomes more collectivist when considering health care decisions of older people and found that participants had a preference for shared decision making. However, within the context of dementia, decisions about what to do or not range in importance: for example, from decisions to be made as a result of a health crisis to decisions to be made about to day to day needs. How decision making is best supported will vary with the circumstances and the complexity and seriousness of the issue in question (Whitlatch et al., 2009).

My thesis will explore factors that might influence decision making in dementia takes account of the family context.

1.8.2 Mental capacity

In England and Wales, the Mental Capacity Act 2005 (MCA) protects and supports people who do not have the ability to make decisions. At its core a set of principles which recognise the rights of people with impaired decision-making capacity caused by mental illness, learning disability, head injury, dementia or related conditions. The act introduced a radical change to the legal concept of capacity, from one which regarded decision-making capacity as 'all or nothing' to one which recognises that capacity is decision specific, relating to the time when a decision or action needs to be taken.

Capacity must be assessed in relation to the decision in question and at the time the decision needs to be made. Capacity is assumed unless evidence suggests the contrary. If there is doubt about an individual's capacity, a capacity assessment must be made to ensure any decision is valid.

To have capacity a person must be able to:

- (i) Understand the information that is relevant to the decision they want to make
- (ii) Retain the information long enough to be able to make the decision
- (iii) Weigh up the information available to make the decision
- (iv) Communicate their decision by any possible means

The principles of the MCA encompass the right of the person [with dementia] to exercise their autonomy as far as possible and require others to support them to do so. The general legal and ethical rule is that people without capacity are treated in

their 'best interests'. Part of what makes up their 'best interests' are their own wishes and preferences as well as what is clinically viewed as the most appropriate action. Where individuals lack capacity, a fundamental consideration is their past wishes and preferences. If these are not recorded or known, relatives are asked about what the person would or not would have wanted. If there is no lasting power of attorney (see next paragraph), the closest relative must be consulted and his or her views only disregarded for a very good reason, such as if they do not seem to be in the patient's best interest or are impossible.

If a person lacks capacity to make their own medical or social decisions, the MCA mandates that a relative who has been given lasting power of attorney can make such decisions. The MCA enables the appointment, through a Lasting Power of Attorney (LPA), of a person or persons to act or make a decision when the person [with dementia] lacks the capacity to do so in their own interests. There are two different types of LPA: property and affairs LPA and health and welfare LPA (Figure 1.3). Alternatively the Court of Protection can appoint a deputy to make decisions and manage the affairs of a person who lacks capacity [a person with dementia] if no LPA has been put in place previously. However, other processes exist to support a person to express and document wishes and preferences for future care; these will be discussed fully in section 1.9.

1.8.3 Decision making – the reality

The work of the Admiral Nurse is centred on the whole family: the person with dementia and their family carers. A major component of support provided is in empowering decision making to enable the family to navigate the various transition points along the journey of dementia, such as seeking a diagnosis, access to

Figure 1.3 Lasting Power of Attorney

Property and affairs LPA

A property and affairs LPA covers decisions about finances and property. This can include various aspects of financial administration, e.g. paying bills, collecting income and benefits, selling a house.

Health and welfare LPA

A health and welfare LPA allows the attorney to make decisions about a donor's* health and welfare. A health and welfare attorney could make decisions about: e.g. place of residence, day-to-day care etc.

Note: * a donor in this context is the person granting LPA to someone else.

support services, admission to a care home, end of life care options, etc. In this section, I will briefly explore how we can work to empower PWD [and carers] to be equal partners in their healthcare and decision making.

Historically, patients [PWD] have been seen in a powerless position with decisions made 'for' them by professionals rather than 'with' them or 'by' them. There has been a history of 'the authority of position' and 'the authority of knowledge' in the health service (Webb et al., 1980; DH, 2005a). Professionals and bureaucratic hierarchies in healthcare have traditionally shaped services, especially in the NHS, and until the early 2000s there was little evidence of patient, carer or consumer participation influencing service development. This started to change radically with the advent of the Patient and Public Involvement movement in the Department of Health with policy (for example, *Creating a Patient Led NHS* (DH, 2005b)), and the growing influence of consumerism throughout society (Williams, 1989). The traditional model of service provision, based mainly on knowledge and professional

decision making, was often experienced by patients and carers as paternalistic and disempowering (Dooher and Byrt, 2002; 2003).

Participation, however, for PWD does not necessarily equate to empowerment and self determination, and may remain an elusive goal (Dooher and Byrt, 2002; 2003; Harrison, 2006). Patient participation in decision making is now viewed as essential to the delivery of individualised and person centred dementia care (Brooker, 2007; DH, 2005b; HMSO, 2005). However, in my clinical experience the involvement and participation of the person with dementia is sometimes little more than lip service paid to an ideal. The issues around decision making for this group of people become more complex as they may progressively lose the capacity to make certain decisions as the disease progresses (as discussed in 1.7.2).

Older people want to be treated in a manner consistent with their own wishes and preferences. They wish to make decisions based upon well presented information and using their personal experience where possible (Popejoy, 2005). As older people often trust loved ones to make healthcare decisions on their behalf (High, 1994), they want those decisions to be in keeping with their wishes and preferences (Roberto, 1999; Whitlatch et al., 2009). In practice, they often wish to keep the burden of decision making upon their family to a minimum and they are often willing to be helped to make decisions in consultation with their doctor (Rosenfeld et al., 2000). Older people's respect for the authority of doctors may be a generational effect, and attitudes may be different in decades to come, but this issue will not be a focus of this thesis.

Successful decision making for a family affected by dementia involves sharing knowledge, experience and wishes and preferences for care across all stakeholders: the person with dementia, the family carers(s) and professionals. In

practice, this might mean a balance between considering the perspectives and wishes of the person with dementia and those of the carer. A core competency domain for Admiral Nursing is in supporting carers to balance the needs of the person with dementia with their own needs, ensuring that equity remains in the partnership, wherever possible (Bunn et al., 2013). In practice it can be challenging to support this balance of interests and needs in end of life care. We have to strive to make the wishes and preferences of the person with dementia influence delivery of care when they may well become at odds with what is in the best interests of the carer.

However, although health and social care systems may aspire to involve PWD in making decisions about their health and social care, in practice attention is often diverted to family carers who wish to pursue proxy decision making.

1.8.4 Family decision making

There is a wealth of literature on family involvement in decision making in health care. Terms vary from study to study with 'family decision maker', 'surrogate decision maker' and 'proxy' used almost interchangeably.

Family carers often experience increasing demands in making decisions as the dementia progresses. Hansen et al. (2004) stated that patterns of decision making differ according to a carer's previous experiences, education, and social and cultural background. Not surprisingly, carers often find decision making difficult and studies have reported on certain practical issues, including: difficulties in deciding what to do about day to day care, distress in making health related decisions (Vig, 2007) and having insufficient information about any possible alternatives and their effects (Hirschman et al., 2006; Mezey et al., 1996).

Wendler and Rid, (2011), conducted a systematic review of surrogate decision making with respect to end of life for incapacitated adults. They found that at least one third of surrogates experienced a negative emotional burden as the result of making treatment decisions. The negative effects on surrogates were often substantial and typically lasted months or, in some cases, years. The most common negative effects cited by surrogates were stress, guilt over the decisions they made, and doubt regarding whether they had made the right decisions but that knowing which treatment is consistent with the patient's preferences was frequently cited as reducing these negative effects. However, as the majority of studies were conducted in the United States of America (USA), these findings may not be transferable to the UK situation where it is not yet common practice to seek the wishes and preferences of older people who still have capacity in developing their plans for future healthcare.

1.8.5 Family decision making for end of life care

Proxy decisions in respect of end of life care in dementia have recently received greater research attention. Studies show that decision making about appropriate end of life care seems to be particularly difficult for family carers. Several influential elements can affect this, such as relationships with professionals, level of trust etc (Caron et al., 2005). However, professional reliance on family decision makers carries the assumption that they can articulate the patient's preferences accurately (Emanuel and Emanuel, 1992). This can lead to the unhelpful situation in which the person with dementia increasingly lacks capacity, the family carers struggle to make decisions on their behalf, and professionals turn to the carer as being the person who knows what to do.

Two recent studies, a systematic review (Kelly et al., 2012) and a meta-analysis (Shalowitz et al., 2006), have contributed significantly to our understanding of

surrogate and proxy decision making and its accuracy for older people and their decision making family member(s).

Kelly et al. (2012) conducted a systematic literature review to identify older peoples goals with respect to treatment decision-making at a time of loss of capacity and to see if these were supported by current practice. They found that the majority of respondents wanted a close family member to act as their decision maker when capacity is lost, with the most common belief that their family member would know which treatments they would want or not. Kelly et al. (2012) found that individuals had three primary goals with respect to making treatment decisions on their behalf:

- (i) involvement of their family
- (ii) treatment that is consistent with their own treatment preferences
- (iii) to reduce the burden of care on their family.

Kelly et al. concluded that current healthcare practice frequently fails to promote individuals' primary goals for treatment in subsequent decision-making.

Shalowitz et al. (2006) undertook a meta-analysis of 16 studies that examined the accuracy of surrogates to predict patients' wishes and preferences for end of life care and treatments. They found that surrogates were able to predict patients' treatment preferences with 68% accuracy. Even discussing wishes and preferences for treatment or designating a person to make decisions on their behalf failed to improve the surrogates' predictive accuracy. Shalowitz et al. (2006) concluded that next-of-kin and patient nominated decision makers incorrectly predict patients' end of life treatment preferences in one third of cases. Thus this evidence questions the

professional and policy claim that reliance on family members in decision making is justified by their ability to predict incapacitated patients' treatment preferences.

When looking at family decision making in end of life care, it has been reported that families in conflict, with poor inter-relational dynamics, were more likely to opt for aggressive care at end of life (Russ and Kaufman, 2005; Winter and Parks, 2008). Winter and Parks (2008) interviewed 68 family proxy decision makers for elderly relatives by telephone and face to face interviews to test the extent to which family discord was associated with preferences for types of end of life care. Their interview schedule assessed preferences for four life-prolonging treatments adapted from the Life Support Preferences Questionnaire (Coppola et al., 1999) for palliative care and included a family discord measure developed for the study, an end of life values scale that included items such as pain management, maintenance of dignity, reluctance to burden family members, avoidance of dependence on others, etc. Analyses showed that greater family discord was associated with stronger preferences for life-prolonging treatments and weaker preferences for palliative care, independently of the end of life values and socio-demographic characteristics of participants. However, when a family is in doubt or uncertain as to what to decide would they err on the side of caution and elect for treatment and intervention for the person with dementia?

Making decisions about end of life care and treatment on behalf of a family member is not straightforward and can at times be extremely difficult. It will often involve complex issues around whether to treat or whether to withhold treatment. There may be several treatment options to choose from, and the context of the decision will also be important (e.g. in a crisis as compared to states of chronic ill-health). Overlaid on this are the perspectives, preferences and wishes for future care of the person for whom decisions are to be made. For clinicians, it will often be difficult to

know whether proxy decision making and treatment choices are consistent with the previously expressed wishes of the older partner/family member with dementia.

1.8.6 Agreement and disagreement between the person with dementia and their carer

As mentioned above, family carers of PWD have to make difficult decisions throughout the course of dementia from soon after its onset until the end of life. This area of decision making is now attracting the attention of clinicians and researchers. Livingston et al. (2010) published the first UK study to investigate what were the most difficult decisions around caring for someone with dementia. There were several domains where decision making was difficult but those around end of life care were particularly difficult and complex for carers, made more difficult in the presence of family disharmony. In the absence of family cohesion the role of the surrogate decision maker becomes isolated and even more difficult.

Literature on agreement between PWD and their family carers for end of life care is limited. Only two studies have explored agreement in the accuracy of a family carer to predict the preferences of the person with dementia. In the first, Whitlatch et al. (2009) examined the psychometric properties of the Values and Preferences Scale (VPS) with 267 PWD and their family carers to determine agreement on values and preferences across a range of fields: burden, safety, quality of care, autonomy and social interaction. They concluded the accuracy of family carers to be 'adequate', but what does 'adequate mean? In the second study, Ayalon et al. (2012) evaluated agreement for end of life preferences between 53 couples, each a person with mild cognitive impairment (MCI) or dementia and their spouses. They used two case vignettes with a 'yes-no' response option to treatment preferences. Ayalon et al. found that the person with MCI or dementia was more likely to opt for treatment than their spouse, with moderate agreement for end of life preferences. In the event

of illness, clinicians may call upon family carers to indicate the treatment preferences of the person with dementia if capacity is lost; so is a moderate level of agreement sufficient with which to base such treatments on?

Both studies had limitations in that they considered agreement alone and not factors that might or might not influence agreement. ANs work with the whole family affected by dementia, with consideration given to the relationship between the care giver and the care recipient. Decisions made for or by the person with dementia cannot be made in isolation from the context of the relationship, such as a wish to be cared for at home at the end of life, so balancing the needs of both parties is important. However, as carer decision making is often the default when a person with dementia lacks decisional capacity, it is important that carers can predict such wishes and preferences as accurately as possible.

1.9 Advance Care Planning

Advance care planning (ACP) has been defined as a process of discussing and recording of wishes, values, and preferences for future care and treatment held between an individual and their care provider(s) (Henry and Seymour, 2007; Froggatt et al., 2008) that takes effect when the person loses capacity (HMSO, 2005). ACP differs from general care planning in that it is usually used in the context of progressive illness and anticipated deterioration.

Advance care planning is a voluntary process of discussion and review to help an individual who has capacity to anticipate how their condition may affect them in the future. If they wish, they can set on record choices about their care and treatment and / or an advance decision to refuse a treatment in specific circumstances, so that these can be referred to by those responsible for their care or treatment (whether professional staff or family carers) in the event that they lose capacity to decide once their illness progresses.

Under the terms of the Mental Capacity Act 2005, formalised outcomes of advance care planning might include one or more of the following:

- i. Advance statements to inform subsequent best interests decisions;
- ii. Advance decisions to refuse treatment, which are legally binding if valid and applicable to the circumstances at hand;
- iii. Appointment of Lasting Powers of Attorney ('health and welfare' and/or 'property and affairs').

There is a small, growing literature on ACP in the UK but the majority is from the USA, Canada, Australia and parts of Europe. In the USA and Canada particularly, ACPs are frequently offered to individuals on admission to long-term care facilities (Molloy et al., 2000b). In the USA all states have some type of ACP legislation, though the specifics of these vary greatly (Scanlon, 2003). Consequently the literature is largely informed by North American research. In the USA, in 1990 the first piece of federal legislation aimed at protecting the rights of individual to make health care decisions, the Patient Self-Determination Act (PSDA), was passed and implemented in 1991 (Douglas and Brown, 2002; Scanlon, 2003). This Act requires hospitals, skilled nursing facilities, home health agencies, hospices, and health maintenance organisations receiving Medicare and Medicaid funding to provide information about ACPs to all patients and to inform them of their right to complete a plan (Berrio and Levesque, 1996; Douglas and Brown, 2002).

Molly and Mepham (1996) evaluated a Canadian programme using the advance planning instrument called 'Let Me Decide'. From a sample of 116 community dwelling older people, 36% completed an ACP during a process that was facilitated by a team of specially trained counsellors. The participants were followed up after six months to determine the status of the plan completion process and to obtain

information regarding their attitudes about the use of ACPs. The authors concluded that the systematic implementation of the 'Let Me Decide' ACP programme among older people was worthwhile and noted that the number having some form of directive had doubled by the end of the study.

ACPs are not *only* about the paperwork and documentation of wishes but are concerned with the opportunity for professionals to instigate and conduct conversations related to death, dying, bereavement and anticipatory loss (Russell, 2014). However, the literature reveals that professionals often lack the confidence and the skills in breaking bad news to initiate the process of advance care planning with sensitivity and empathy (Lacey, 2005).

In comparison with other countries, research in the UK on the development of ACP is at an earlier stage (Froggatt et al., 2009). There is also the distinct health care context of the National Health Service which largely provides care free at the point of access. Previous ACP research from the UK has found that earlier discussions in a life limiting illness can help to reduce anxiety about death (Pemberton et al, 2003; Storey et al., 2011) and lead to an increase in feelings of autonomy (Bisson et al., 2009), maintenance of control (Singer et al., 1998), patient satisfaction (Tierney et al., 2001), and a range of improved outcomes for family carers, such as reduced depression, stress and anxiety (Detering et al., 2010).

People with a life-limiting illness, especially dementia, are not routinely consulted about their wishes and preferences for future care. Berrio and Levesque (1996) suggested several potential barriers that may hinder the completion of an ACP:

- Procrastination, or waiting to do it later
- Dependence on family for decision making

- Lack of knowledge about ACP
- Difficult of talking about the subject
- Waiting for the healthcare professional to initiate a discussion by the patient
- Waiting for the patient to initiate discussion by the health professional
- Believing a lawyer is needed to fill out the forms
- Fatalism, or acceptance of the 'will of God'
- Fear of 'signing my life away'
- Fear of not being treated

Many of these barriers still exist. As we have discussed (section 1.5.7), there may be other reasons why these discussions do not take place in dementia care: for example, acknowledgement that dementia is a terminal/life-limiting illness or care professionals lack of confidence in starting discussions (Lacey, 2005; Caplan et al., 2006; Froggatt et al., 2009).

As discussed (section 1.6.1), in the UK, the Department of Health emphasised the central importance of ACP in the *End of Life Care Strategy* (DH, 2008) by stating that everyone affected by life limiting or life threatening illness should be offered advance care planning. Although there is ample literature examining the use and effectiveness of advance directives and advance care planning at or near the end of life in other long term conditions, little has been studied about ACPs in terms of their application in dementia and the ability of family members to predict future wishes.

1.10 Summary

In conclusion, there will be large numbers of PWD in the UK as the population continues to age (1.5.3). Dementia is a progressive, irreversible neurodegenerative condition that greatly reduces life with one in three of the population expected to die

with or from dementia (1.5.7). Literature suggests that people with non-malignant disease, such as dementia, [and their families] are much in need of palliative care services, especially through advance care planning and decision making in preparation for end of life (1.6).

Dementia care is underpinned by the philosophical application of autonomy as espoused within the principles of person centred and relationship centred care (1.7). UK law and policy is also becoming a major influence on autonomy and control in end of life care through recommending improved access to palliative care and advance care planning (1.6 and 1.8). The process of advance care planning in dementia is far from straightforward; as dementia progresses, the ability to consider future thoughts and actions becomes compromised, thus affecting decision making abilities. Family carers find themselves increasingly in a position whereby they are called on to inform, or directly make, decisions on behalf of the person with dementia. It is often assumed they know what the person with dementia's decisions might have been when capacity is lost even though wishes and preferences have not been articulated. There is some literature on the complexity of family, proxy decision making in older populations but very little where dementia is involved (1.7.5). There is also little evidence to help understand issues concerning the ability of family members to predict the future wishes and preferences of a person with dementia and factors that influence their accuracy (1.8.6).

The primary aim of my research is to better inform the process of advance care planning and explore whether family carers of a person dementia can accurately predict their wishes and preferences for end of life care and to examine factors that might influence this. In the following chapter I report the findings of a systematic review of the literature, relating specifically to advance care planning in dementia.

CHAPTER 2

**ADVANCE CARE PLANNING FOR PEOPLE WITH
DEMENTIA: A SYSTEMATIC REVIEW OF THE
LITERATURE**

I completed my initial literature review in 2011 in order to shape and inform the direction of my research and published the findings (Harrison Denning et al., 2011)⁵. However, as this has been a part-time doctoral study and several years have elapsed, I have updated the review and combined recent findings alongside the earlier data.

2.1 Aims

The aim was to evaluate the evidence base for advance care planning in dementia to include the perspectives of PWD, their family carers and involved professionals. A secondary aim was to explore the methodologies used in order to inform the qualitative and quantitative phases of my study.

Several specific questions were posed in considering the literature:

1. How large is the evidence base for advance care planning for PWD?
2. What kinds of methodologies have previously been used?
3. What level of cognition is required to develop an advance care plan?
4. Is advance care planning effective in changing outcomes?

2.2 Method

2.2.1 Search Strategy

I performed an electronic search for all relevant publications up to 31st December 2013 using the following electronic bibliographic databases:

- Cochrane Library (from 1992)

⁵ Appendix 1: Harrison Denning, K., Jones, L. & Sampson, E.L. (2011) Advance Care Planning for people with dementia: A review. *International Psychogeriatrics*, 23 (10): 1535-51)

- CINAHL (from 1982)
- AMED (from 1985)
- PubMed (from 1950)
- PsychINFO (from 1984)
- EMBASE (from 1974)
- BNI (from 1994)
- SIGLE (from 1980)
- Conference proceedings (Conference Papers Index)
- Internet searches using Google search engine

2.2.2 Personal searches

Additional articles were sought from the reference lists in each paper included in the review. Experts (n = 7) in the field were also contacted and asked if they knew of any current studies or unpublished materials. I hand searched reference lists in papers for authors and journals that appeared frequently in the results.

2.2.3 Inclusion criteria

As I believed there would be a limited evidence base, broad inclusion criteria were used in the early scoping of the literature to include studies of advance care planning involving PWD and their family carers or professionals. The following criteria were considered essential for inclusion:

- Published in English language
- Involved PWD (diagnosed clinically or using research criteria)
- Any study methodology
- Provides:

Characteristics of the population studied

Details about the type of advance care planning under investigation

Information about the study setting

2.2.4 Exclusion criteria

- Not written in English
- Single case studies, dissertation abstracts, secondary research opinion and comments

2.2.5 Search terms

The literature search was developed using the PubMed database. The term “Advance Care Planning” was the overarching intervention heading and was searched as both free text and as a Medical Subject (MeSH) heading. The MeSH heading for this includes “advance directives” and “living wills” within the MeSH tree.

Similarly “dementia” was also entered as free text and a MeSH heading. The terms (both MeSH and free text) were combined with the “AND” operand and searched initially in the PubMed database. Searches were then translated and repeated in the other databases.

2.2.6 Recording of search

Records were kept of numbers of titles and abstracts screened, papers retrieved, papers rejected at this point and studies suitable for inclusion. Assessments erred on the side of inclusiveness. Abstracts and brief citation from databases were assessed and filed in a bibliographic management package (RefMan 12).

2.2.7 Selection method

I performed the initial selection of papers for inclusion on the basis of titles and abstracts. Full articles were obtained and read for those appearing to fulfil the broad

inclusion criteria. A second selection was then made through consensus, between me and my supervisor (ELS).

2.2.8 Critical appraisal of papers

The final papers were reviewed using a template appropriate to the study methodology of the paper; qualitative, quantitative or mixed (Table 2.1) thus ensuring a comprehensive and transparent review methodology so that the process was systematic, robust and replicable. We recorded the following information: nature and size of sample, study methodology used, type of intervention and its effectiveness.

Qualitative and quantitative methodologies were evaluated using two frameworks to assess study quality. For studies whose methodology was largely qualitative the SCIE Systematic Research Review framework (Coren and Fisher, 2006) was adopted (Appendix 2). This framework has been developed specifically to apply methodological rigour in qualitative studies.

We used criteria to evaluate prevalence studies (Boyle, 1998) (Appendix 3). This guideline provided a framework to evaluate, specifically, the sampling methods to ensure clear definition of the target population; the instruments and methods used for measurements; and the rigour of analysis. Where mixed methods were used in a study then both frameworks were completed.

2.3 Results

2.3.1 Initial literature search (up to 31st March 2010)

A total of 344 papers were identified (see figure 2.1) up to a final date of 31st March 2010. A further 23 papers were retrieved from the period between the initial search of 31st March 2010 to 31st December 2013 (Figure 2.1). This total includes two papers that were identified by scrutiny of reference lists of the papers from the initial search. Yields from different databases were recorded: Cochrane (n = 0); AMED (n = 24); CINAHL (n = 237); EMBASE (n = 3); BNI (n = 1); PubMed (n = 335); SIGLE (n = 0); PsychInfo (n = 0). Duplicate references were found largely between PubMed and CINAHL databases. Other papers were excluded because they were not written in English (n = 13). There were a large number of editorials, syntheses of expert opinion, comments, letters, case studies (n = 105) which were all excluded.

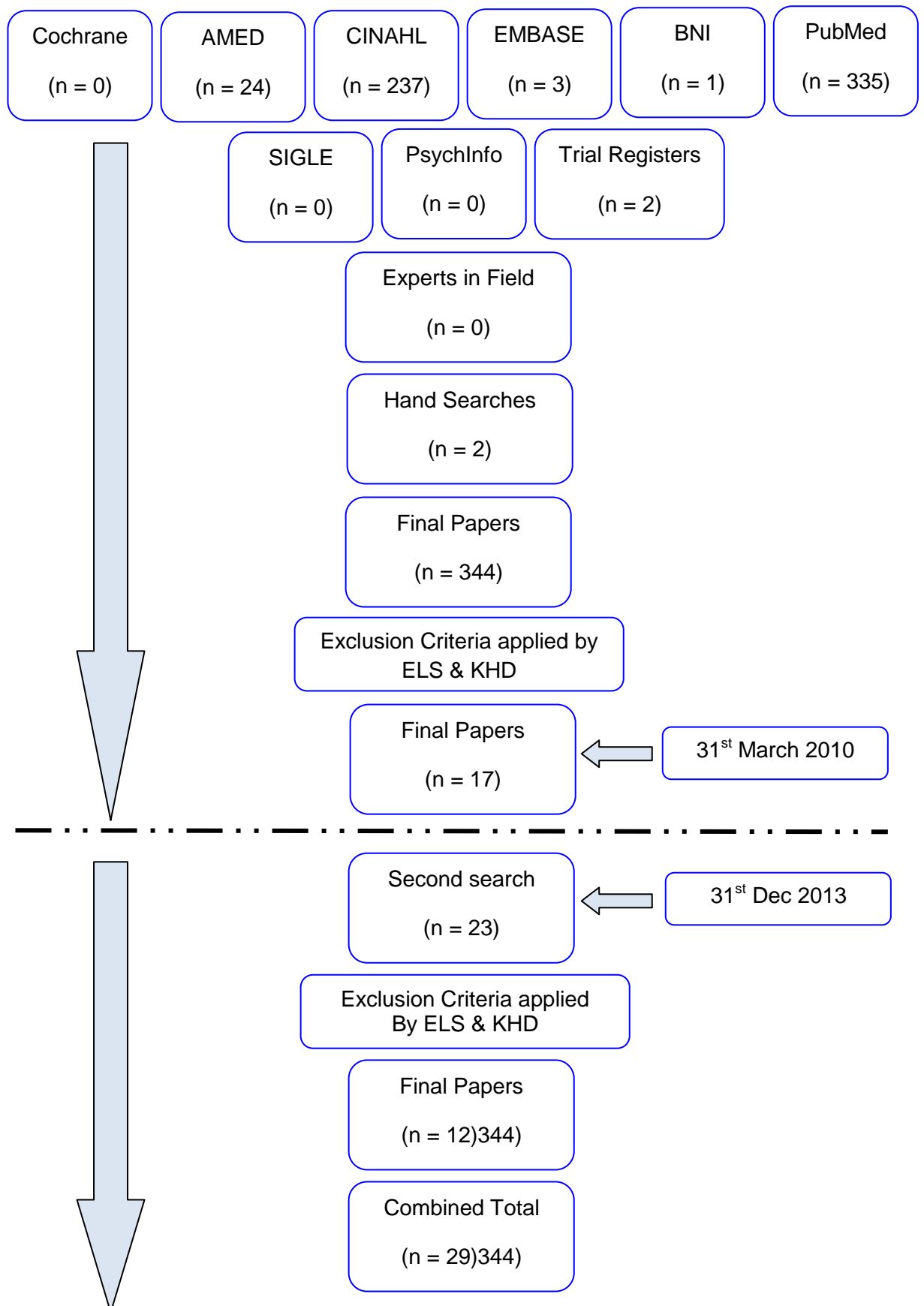
Abstracts for all retrieved citations were requested; but of these a large number were unavailable (n = 158) even through the British Library, these were predominantly the older literature (pre 1995).

Of the preliminary selected papers, where the title or the abstract of the study appeared relevant, the full articles were sought. The reference lists of selected papers were scrutinised for further secondary references, this yielded a further two papers. Hand searching of frequently appearing journals was considered but there was no single journal that was more frequently represented.

2.3.3 Included studies

Finally, 29 papers, from both the initial and secondary reviews were selected through a process of my supervisor and myself individually reading and reaching

Figure 2.1 Results of literature searches



agreement for their inclusion or exclusion based on the defined criteria (2.2.7). All those that fitted the inclusion criteria are presented, ordered by the research methods employed; qualitative (Table 2.1), quantitative (Table 2.2) and mixed methods (Table 2.3). The tables indicate each paper's aims, methodologies, population and sample sizes, measurements and tools used, the length of time for study, intervention (where appropriate), study setting and outcome(s). These papers were characterised and described according to the methodology used.

The earliest of the final papers selected for review was published in 1991 (Finucane et al., 1991) and the most recent in 2013 (De Gendt et al., 2013; Dickinson et al., 2013; Goodman et al., 2013; Livingston et al., 2013; Poppe et al., 2013; Robinson et al., 2013) (see figure 2.2). In the initial stage of this review only three (18%) of included studies came from the UK, the majority from North America (n = 12, 71%).

In the updated section of the review seven of the included 12 studies were from the UK, showing a marked increase in research in this field in the UK over the ensuing three year period (Figure 2.2). Europe overall (including the UK) accounted for four (24%) of the studies reviewed with a single study from Australia.

2.3.2. Methodologies of included studies

2.3.2.1 Qualitative studies

I defined qualitative research as “a field of inquiry applicable to many disciplines and topics that aim to gather an in-depth understanding of human behaviour and the reasons that govern such behaviour” (Denzin and Lincoln, 2000). Only one study employed qualitative methods alone (Forbes et al., 2000) in the initial review. In their study Forbes et al used focus groups to describe family decision making

Figure 2.2 A timeline of included papers

1991	Finucane et al	
1996	Mezey et al	
1999	Fazel et al	UK
<hr/>		
2000	Fazel et al	UK
	Forbes et al	
2002	Cavalierrri et al	
2004	Hirschman et al	
	Haydar et al	
2005	Rurup et al	
2006	Lacey	
	Hirschman et al	
	Caplan et al	
2007	Gregory et al	UK
	Karel et al	
2008	Lingler et al	
	Hirschman et al	
	Triplett et al	
<hr/>		
2011	Sampson et al	UK
	Vandervoort et al	
	Gerand et al	
2012	Harrison Dening et al	UK
	Livingston et al	UK
	Ayalon et al	
2013	Poppe et al	UK
	Dickinson et al	UK
	Goodman et al	UK
	De Gendt et al	
	Robinson et al	UK
	Livingston et al	UK

processes in each of four participating care facilities (Table 2.1). Content thematic analysis was used to describe and synthesise data from qualitative studies.

The update to this review in December 2013 revealed a further five qualitative studies (Table 2.1). A range of methods were used to collect data including focus groups (Robinson et al., 2013), interviews (Livingston et al., 2012; Dickinson et al., 2013; Poppe et al., 2013; Robinson et al., 2013) and guided conversations (Goodman et al., 2013). Three papers are from the same group of authors who have described different samples from the same dataset or programme of research but are included as two separate contributions (**see table 2.1).

Most of the qualitative studies aimed to understand factors that influenced advance care planning from the perspectives of PWD, family carers and professionals involved in their care.

Table 2.1 Studies using qualitative methodologies

Paper	Aims	Methodology	Tools used in recruitment	Sample size	Study date and duration	Intervention	Tools used in methods	Study Setting	Outcomes measured
Qualitative methodologies									
Forbes et al. (2000) USA	To describe decision making regarding end of life treatments.	Focus Groups	Minimum Data Set (USA); CPS	Total 28 20 f 8 m	Not indicated	NA	None	Nursing homes	Complexities and processes that influence end-of life decisions.
Livingston et al. (2012) UK**	To examine barriers and facilitators to care home staff delivering improved end of life care for people with dementia.	Individual interviews		Total 58 44 f 14 m	Not indicated	NA	None	Nursing Home	Barriers and facilitators to improve end of life care.
Robinson et al. (2013) UK**	To explore professionals' experiences on the implementation of ACP.	Focus groups and individual interviews	NA	Total 95 14 focus Groups 18 interviews	Sept 2009 to January 2011	NA	None	Palliative care and dementia care across a range of settings	Factors that influence the implementation of advance care planning.
Dickinson et al. (2013) UK**	To explore the views and experiences of people with dementia and family carers on the content, process and timing of ACP	Semi structured interviews	MMSE	Total 46 17 PWD 29 carers	Not indicated	NA	None	Older peoples services	Understanding the needs of PWD and their family carers to enable ACP.
Poppe et al. (2013) UK	To explore the acceptability of ACP discussions with people with memory problems and mild dementia	In depth interviews.	Diagnostic assessment	Total 193 18 PWD	Not indicated	NA	ACP-ED	Two memory services	To understand the utility of the ACP-ED tool to support ACP in early dementia.

Paper	Aims	Methodology	Tools used in recruitment	Sample size	Study date and duration	Intervention	Tools used in methods	Study Setting	Outcomes measured
	shortly after diagnosis.			25 carers 150 staff members					
Goodman et al. (2013) UK	To explore how older PWD discuss their priorities and preferences for end of life care.	Guided conversations	DDS	Total 18 13 f 5 m	Not indicated	NA	None	Care homes.	To inform discussions on planning ahead for families and practitioners.

Note: ACP = Advance Care Planning; CPS = Cognitive Performance Scale; PWD = people with dementia; Mini Mental State Examination; ACP-ED = Advanced Care Planning in Early Dementia; DDS = Disability and Dementia Scale. ■ ■ ■ Studies below line were retrieved during the second literature search

2.3.2.2 Quantitative studies

We defined quantitative studies “the systematic, scientific investigation of quantitative properties and phenomena and their relationships” (Parahoo, 2010). The objective of quantitative research is to develop and employ mathematical models, theories and/or hypotheses pertaining to natural phenomena. The process of measurement is central to quantitative research because it provides the fundamental connection between empirical observation and mathematical expression of quantitative relationships (Parahoo, 2010).

Of the studies that employed only quantitative methods (n = 15) 11 were retrieved in the search up to March 2010 and four subsequently up to December 2013 (Table 2.2). Four used control or comparative groups (Caplan et al., 2006; Cavallieri et al., 2002; Fazel et al., 1999, 2000; Haydar et al., 2004). One study by Cavallieri et al. (2002) surveyed primary care physicians to explore whether ACP discussions were being held. Two studies compared those with dementia with participants who were cognitively intact (Fazel et al., 1999; 2000) and one compared PWD to those with congestive cardiac failure (Haydar et al., 2004). Caplan et al. (2006) undertook a controlled evaluation of advance care planning in care homes.

Other methods employed were cross sectional study (Gregory et al., 2007; Lingler et al., 2008; Lacey, 2005; Rurup et al., 2006). Gregory et al. (2007) used this methodology to determine if the degree of an individuals’ cognitive impairment related to their capacity to appoint an enduring power of attorney. Lingler et al. (2008) used a retrospective cross sectional method using semi-structured interviews of people with a cognitive impairment to assess prevalence of advance care planning. Two studies (Lacey, 2005; Rurup et al., 2006) used survey or questionnaire based studies to explore attitudes and perceptions of professionals.

Two studies examined prevalence of advance care plans and advance directives (Garand et al., 2011; Triplett et al., 2008). Triplett et al. used a prospective longitudinal study of case records to examine the prevalence of advance directives. Garand et al. (2011) undertook a retrospective analysis of the increase in prevalence of ACP over time in a sample of 127 people with a diagnosis of mild cognitive impairment (MCI) or Alzheimer's disease. Mezey et al. (2000) conducted a prospective study interviewing carers of PWD to determine preferences about life sustaining treatment options. Two Belgian studies used retrospective cross sectional methods to examine the prevalence of advance directives in nursing homes and clinical characteristics of deceased patients (De Gendt et al., 2013; Vandervoort et al., 2012). Finally, in an Israeli study, Ayalon et al. (2012) used a cross sectional sample of 53 couples to evaluate the degree of agreement for end of life treatment between the patients' preferences and those of their spouses.

Table 2.2 Studies using quantitative methodologies

Paper	Aims	Methodology	Tools used in recruitment	Sample size	Study date and duration	Intervention	Tools used in methods	Study Setting	Outcomes measured
Quantitative methodologies									
Mezey et al. (1996) USA	To examine the anticipated decisions to consent to or forgo life sustaining treatment of carers of people with dementia	Prospective cohort	GDS ² Stage 4 AD	Total 50 32 f 18 m	Not indicated	NA	GDS ² CBI	Aging and Dementia Research Centre	Influence of spouse characteristics in proxy decision making
Fazel et al. (1999) UK	To examine the influence of cognitive impairment, pre morbid intelligence and decision making capacity to complete ADs on treatment preferences for life sustaining medical therapy.	Cross sectional, control	MMSE	Total 100 57 f 43 m	Not indicated	NA	Purposely developed semi structured interview schedule to assess capacity. Three clinical vignettes.	Community psycho geriatric teams	Psychometric properties of competence assessment.
Fazel et al. (2000) UK	Control, semi structured interview following presentation of vignettes relating to end of life.	Cross sectional, control	DSM-IV MMSE NART	Total 100 57 f 43 m	Not indicated	NA	Purposely developed semi structured interview schedule to assess capacity. Three clinical vignettes.	Community psycho geriatric teams	Life sustaining treatment decisions and relationship to cognitive function.

Paper	Aims	Methodology	Tools used in recruitment	Sample size	Study date and duration	Intervention	Tools used in methods	Study Setting	Outcomes measured
Cavalieri et al. (2002) USA	To assess if advance care planning was offered to people with dementia.	Survey	None	Total 271	Not indicated	NA	Purposely designed survey tool	Primary care	Practice patterns for advance care planning and advance directives.
Haydar et al. (2004) USA	Retrospective case-control study Medical records of patients who had enrolled in Elder House Calls Programme to compare end of life preferences in people with dementia and congestive cardiac failure	Retrospective case control	CDR ADL & IADL	Total 142 142 from a larger sample of 453 (219 f, 234 m)	Oct 1996 – Apr 2001	NA	Purposely developed semi structured interview schedule.	Geriatrician led house call programme	Differences in end of life care preferences.
Rurup et al. (2005) Holland	To investigate the attitudes of physicians, nurses and relatives towards medical end of life decisions concerning patients with dementia.	Observational study based on questionnaires	None	Total 389 Physicians 75 Relatives 136 Nurses 178	2000	NA	Purposely developed questionnaire BAN-S	Nursing home	Attitudes towards end of life decisions
Caplan et al. (2006) Australia	To evaluate a system of educating families, staff and GPs about dementia and ACPs	Controlled evaluation of an intervention	MMSE DASCCAD	19 care homes: uncertain number of residents	5 years	Clinical Nurse Specialist	Let Me Decide advance care directive	Nursing homes	Hospitalisation rates and mortality
Lacey (2006) USA	To describe nursing home social services staff roles and perceptions related to end of life decision making for nursing home residents in end stage dementia.	Descriptive analysis	None	Total 135 124 f 11 m	Not indicated	NA	Purposely designed questionnaire	Nursing home	Staff attitudes and knowledge of end-life-decisions.

Paper	Aims	Methodology	Tools used in recruitment	Sample size	Study date and duration	Intervention	Tools used in methods	Study Setting	Outcomes measured
Gregory et al. (2007) UK	To investigate if capacity to create an EPA is significantly related to the degree of cognitive impairment in Alzheimer patients	Cross sectional, descriptive	DSM-IV MMSE	Total 74 49 f 25 m	Jan 2005 - Jan 2006	NA	Semi structured interview schedule to assess capacity.	Old age psychiatry consultant team	Sensitivity of MMSE scores to predict capacity status.
Lingler et al. (2008) USA	To assess Durable Power of Attorney (DPOA) and living will (LW) status on presentation for assessment / evaluation.	Retrospective , cross sectional study using semi structured interviews	Consensus based MCI, probable AD MMSE	Total 745 473 f 272 m	1 st Jan 2000 to 31 st Aug 2005	NA	Purposely developed semi structured interview schedule.	Memory Disorders Clinic	Correlation of prevalence and socio demographics of ACP
Triplett et al. (2008) USA	To examine how people with end stage dementia have conveyed their wishes for end of life care in advance directives	Prospective longitudinal study of case records	Local criteria for end stages of life	Total 123 68 f 55 m	Dec 2000 to Aug 2003	NA	None	Nursing home	Documentation of advance directives
Garand et al. (2011) USA	To examine ACP completion patterns at diagnosis of dementia and then at follow up.	Retrospective analysis of data that had been prospectively collected.	MMSE	Total 127 73 f 54 m	January 2000 to August 2005	NA	None	ADRC memory Disorders Clinic	ACP completion rates over time following diagnosis.
Ayalon et al. (2012) Israel	To evaluate concordance in end of life preferences between people with MCI or dementia and their spouses.	Cross-sectional sample	DSM-IV MMSE	Total 102 (53 couples) 53 f 53 m	Not indicated	NA	Two case vignettes representing common end of life scenarios	Two psycho-geriatric clinics	Spousal agreement.

Paper	Aims	Methodology	Tools used in recruitment	Sample size	Study date and duration	Intervention	Tools used in methods	Study Setting	Outcomes measured
Vandervoort et al. (2012) Belgium*	To describe the prevalence of documented AD among nursing home residents with dementia.	Retrospective cross-sectional post-mortem survey	Sought the diagnosis from assigned nurse	Total 764 551 f 210 m	Sept to Oct 2006	NA	Katz ADL scale, BESADL, ESAS	Nursing Homes	Prevalence of Advance Directives and GP treatment orders and associated outcomes.
De Gendt et al. (2013) Belgium*	To investigate the prevalence and characteristics of documented advance directives and physicians' orders for end-of-life care in nursing homes.	Retrospective cross-sectional survey	Sought the diagnosis from assigned nurse	Total 1240 852 f 384 m	Sept to Oct 2006	NA	None	Nursing Homes	Prevalence of Advance Directives in relation to clinical characteristics and care received.

Note: CPS = Cognitive Performance Scale. MMSE = Mini Mental State Examination. ADL = Activities of Daily Living. IADL = Instrument of Activities of Daily Living. SCB = Screen for Caregiver Burden. CDR = Clinical Dementia Rating. NART = National Adult Reading Test. DRG = Diagnosis Related Group. TICS = Telephone Interview for Cognitive Status. GDS = Geriatric Depression Scale¹. BSI = Brief Symptom Inventory. DDSQ = Dementia Diagnostic Screening Questionnaire. HSQ = Health Screening Questionnaire. GDS² = Global Deterioration Scale. BI = Burden Inventory. BAN-S = Bedford Alzheimer nursing severity sub-scale. NINCDS-ADRDA = National Institute of Neurological and Communicative Disorders and Stroke – Alzheimer's disease and Related Disorders Association criteria. ADRC = Alzheimer's disease Research Centre. MCI = Mild Cognitive Impairment. Katz ADL = Katz Activities of Daily Living. BESADL = Belgian Evaluation Scale for Activities of Daily Living. ESAS = Edmonton Symptom Assessment Scale. AD = Advance Directives.

■ ■ ■ Studies below line were retrieved during the second literature search

* Two papers reporting from the same study

2.3.2.3 Mixed method studies

Eight studies used a mixed method approach using both quantitative and qualitative elements. For the purposes of this thesis, mixed methods research is defined as “a research approach that employs quantitative research to assess the magnitude and frequency of constructs and rigorous qualitative research to explore the meaning and understanding of such constructs” (Johnson et al., 2007).

Five studies were retrieved in the initial search (Finucane et al., 1991; Hirschman et al., 2004; 2006; Karel et al., 2007) and three in the second (Sampson et al., 2011; Harrison Dening et al., 2012; Livingston et al., 2013) (Table 2.3).

Finucane et al. (1991) used semi-structured interviews to determine whether asking PWD specific questions about hypothetical future illness was burdensome to them and then to measure the consistency of responses over time. He also interviewed carers to identify any distress of PWD or carers caused by the interview process. Hirschman et al. (2004) employed a prospective observational cohort study recruiting dyads of PWD and their carers to observe changes in decision making over time. In a second study Hirschman et al. (2006) used semi-structured interviews with family carers to determine current decision making and past healthcare discussion experiences employing both qualitative and quantitative methods of analysis. In a third study Hirschman et al. (2008) again conducted semi-structured interviews to identify what standard of decision making was employed in the same target population and again, used both qualitative and quantitative methods of analysis. Karel et al. (2007) used a non-randomised control methodology using cognitively intact people as the control group to explore potential benefits and pitfalls of approaches for values assessment in advance care planning. Part of the process involved a semi-structured interview schedule and thematic content analysis of the data.

In the studies retrieved in the second literature search, Sampson et al. (2011) piloted an exploratory randomised controlled trial of a palliative and advance care plan intervention for people with severe dementia admitted to acute hospital care (n = 33). The intervention comprised a palliative care assessment to inform ACP discussions with the family carer. Carer-patient dyads were randomised into 'usual care' or the intervention. Both quantitative and qualitative methods were used to develop the intervention. Livingston et al. (2013) conducted a small non-randomised study of an interactive training intervention for nursing home staff. The outcomes examined were documented advance care wishes and residents' place of death. They also conducted a thematic review of pre- and post-intervention interviews. Finally, I undertook a mixed methods study using a modified nominal group technique (NGT) and thematic content analysis of group discussions to explore whether PWD (n = 9) and carers (n = 8) were able to generate and prioritise preferences for end of life care (Harrison Denning et al., 2012, described in detail in Chapter 3 of this thesis).

Table 2.3 Studies using mixed methodologies

Paper	Aims	Methodology	Tools used in recruitment	Sample size	Study date and duration	Intervention	Tools used in methods	Study Setting	Outcomes measured
Mixed methodologies									
Finucane et al. (1991) USA	To determine burden when presented with decision making about 3 hypothetical scenarios relating to end of life.	Semi structured interviews	MMSE	6 dyads	Not indicated	NA	None	Alzheimer's disease support group	Advance planning and distress.
Hirschman et al. (2004) USA	To assess Alzheimer's disease patients' participation in decision making about medical care, detecting any shifts over time and whether changes were associated with changes in dementia or caregiver characteristics	Prospective observational cohort	NINCDS-ADRDA MMSE SCB	Total 77 Patients 45 f 32 m Total 77 Carers 54 f 23 m	Feb 2000 –Feb 2003	NA	Purposely developed interview schedule	Memory Disorders Clinic	Decision making and associations with decline of person with dementia and patient carer characteristics.
Hirschman et al. (2006) USA	To identify what standards for decision making are used by family carers of people with advanced dementia	Semi-structured interviews	DRG code 290.0 MMSE	Total 30 16 f 14 m	Not indicated	NA	Purposely developed semi structured interview schedule	Alzheimer's Disease Centre	Legal and ethical hierarchy in decision making

Paper	Aims	Methodology	Tools used in recruitment	Sample size	Study date and duration	Intervention	Tools used in methods	Study Setting	Outcomes measured
Hirschman et al. (2008) USA	To identify factors that facilitate or hinder advance planning for persons with dementia	Semi-structured interviews	DRG code 290.0 MMSE	Total 30 16 f 14 m	Not indicated	NA	Purposely developed semi structured interview schedule	Alzheimer's Disease Centre & Long term care facility	Facilitators and inhibitors to advance care planning
Karel et al. (2007) USA	Examination of three methods for asking participants to communicate values and preferences related to future medical care decisions	Longitudinal controlled study	DSM IV TICS GDS ¹ BSI DDSQ HSQ	Total 176 88 f 88 m	Not indicated	NA	HCVS: FCI HCVSC	Community	The use of values clarification in advance care planning.
Sampson et al. (2011) UK	To assess the feasibility of implementing a two-component intervention to improve end of life care for people with advanced dementia.	Two-arm feasibility randomised controlled trial of a complex intervention	FAST	Total 33 33 PWD 17 carers	Not indicated	Palliative care assessment to inform ACP	CAM Waterlow , Stirling Abbey scales PACSLA C Doloplus K10, EQ-5D, DCS DSI, SAS LSQ, SW C- EOLCD CSQ	Acute hospital medical wards	The feasibility of and intervention to support ACP in advanced dementia.

Paper	Aims	Methodology	Tools used in recruitment	Sample size	Study date and duration	Intervention	Tools used in methods	Study Setting	Outcomes measured
Harrison Denning et al. (2012) UK	To explore whether PWD and their carers were able to generate and prioritise preferences for care.	Modified Nominal Group Technique and thematic content analysis	MMSE	Total 17 PWD 9 6 f 3 m Carers 8 5 f 3 m	Oct 2009 to Jan 2010	NA	None	Memory assessment clinic	How PWD and carers each define their own wishes and preferences and whether the expression of these is facilitated or hindered by the carer being present.
Livingston et al. (2013) UK	To improve end of life care for people with dementia in care homes by increasing the implementation of advanced care wishes.	Intervention of ten-session manualised interactive training program for staff and qualitative interviews with staff and family carers.	None.	Total 98 residents 53 relatives Staff demographics reported elsewhere	Not indicated	Ten-session manualised interactive training program for staff	QoL-AD GHQ	Nursing Home	Increase in documented advance care plans for residents, increased confidence in staff in care planning and increased consultation and satisfaction amongst family carers about decisions.

Note: CPS = Cognitive Performance Scale. MMSE = Mini Mental State Examination. ADL = Activities of Daily Living. IADL = Instrument of Activities of Daily Living. SCB = Screen for Caregiver Burden. CDR = Clinical Dementia Rating. NART = National Adult Reading Test. DRG = Diagnosis Related Group. TICS = Telephone Interview for Cognitive Status. GDS = Geriatric Depression Scale¹. BSI = Brief Symptom Inventory. DDSQ = Dementia Diagnostic Screening Questionnaire. HSQ = Health Screening Questionnaire. GDS² = Global Deterioration Scale. BI = Burden Inventory. BAN-S = Bedford Alzheimer Nursing Severity sub-scale. NINCDS-ADRDA = National Institute of Neurological and Communicative Disorders and Stroke – Alzheimer’s Disease and Related Disorders Association criteria. HCVS: FCI = Health Care Values Survey: Forced Choice Items. HCVSI = Health Care Values Scale Items. FAST = Functional Assessment Staging Tool. ACP = Advance Care Planning. CAF = Confusion Assessment Method. PACSLAC = Pain Assessment Checklist for Seniors with Limited Ability to Communicate. K10 = Kessler Distress Scale. EQ-5D = Euroqual-5D. DCS = Decision Conflict Scale. DSI – Decision Satisfaction Inventory. SAS = State Anger Scale. LSQ = Life Satisfaction Scale. SWC = Satisfaction with End of Life Care in Advanced Dementia Scale. CSQ = Carer Strain Questionnaire. QoL-AD = Quality of Life in Alzheimer’s Disease. GHQ – General Health Questionnaire.

— • — Studies below line were retrieved during the second literature search

2.3.3 Samples

Sample sizes varied greatly (range 6 – 1240). The smallest sample used a mixed method approach involving interviews with six dyads of PWD and their carer (Finucane et al., 1991) and the largest involved 1240 residents across 594 nursing homes in Belgium (De Gendt et al., 2013; Lingler et al., 2008). As would be expected larger sample sizes were more likely to be found in the quantitative studies. Most studies provided further descriptive data on their samples, e.g. gender (n = 22, 76%); age (n = 23, 79%); ethnicity (n = 12, 41%); education (n = 14, 48%); professional role; relationship of carer to person with dementia (n = 11, 38%); level of cognitive function as indicated by tools (n = 12, 41%) (Mini Mental State Examination (MMSE); Cognitive Performance Scale (CPS), etc).

2.3.4 Diagnosis and assessment of cognitive impairment and dementia

Almost a third of the studies (n = 9, 31%) used a clinical diagnosis of dementia (Finucane et al., 1991; Garand et al., 2000; Haydar et al., 2004; Hirschman et al., 2004; 2006; 2008; Caplan et al., 2006; Triplett et al., 2008). Other studies used recognised diagnostic criteria for dementia: DSM-IV (American Psychiatric Association, 1994) (n = 4, 14%), (Fazel et al., 1999; 2000; Gregory et al., 2007; Karel et al., 2007); two (n = 2, 7%) the Diagnosis Related Group (DRG) (Hirschman et al., 2006; 2008; two (n = 2, 7%) the National Institute of Neurological and Communicative Disorders and Stroke – Alzheimer’s Disease and Related Disorders Association Criteria (NINCDS-ADRDA) (Haydar et al., 2004) one used the USA Minimum Data Set (Forbes et al., 2000), and one using ICD-10 (WHO, 1992) (Harrison Denning et al., 2012).

Several studies assessed the severity of the dementia. The MMSE (Folstein et al., 1975) being the most frequently used cognition scale (n = 13, 45%), used either as

part of the data indicating the sample selection or in assessing outcomes. Others used were CPS (n = 1), Clinical Dementia Rating (CDR) (n = 1), Geriatric Depression Scale GDS (n = 1), Bedford Alzheimer Nursing Severity sub-scale (BAN-S) (n = 1), Telephone Interview for Cognitive Status (TICS) (n = 1), Dementia Diagnostic Screening Questionnaire (DDSQ) (n = 1). Three studies (Haydar et al., 2004; Sampson et al., 2011; Vandervoort et al., 2012) used Activities of Daily Living (ADL) and Instrument of Activities of Daily Living (IADL) functional assessments scales. There was a distinct variation in tools used which makes it difficult to define the population studied in a systematic review.

Several studies included only people with a diagnosis of 'Alzheimer's disease' with only one study indicating other diagnostic subtypes of dementia (Harrison Denning et al., 2012). No studies retrieved explored if there were any differences between advance care planning outcomes across diagnostic sub groups of dementia.

2.3.5 Outcomes measured

A range of descriptors were used. Eleven (n = 11, 38%) studies evaluated factors that may facilitate or inhibit end of life care decisions (Fazel et al., 2000; Hirschman et al., 2004; 2006; 2008; Karel et al., 2007; Lingler et al., 2008). Three studies evaluated staff attitudes in relation to end of life care decisions in dementia (Lacey, 2005; Rurup et al., 2006).

Three studies investigated the use of the MMSE in an attempt to predict a 'cut off range' that may indicate a point at where a person with dementia may no longer have decision making capacity (Fazel et al., 1999; Gregory et al., 2007; Hirschman et al., 2004).

Outcomes measured in the studies retrieved in the second literature search demonstrated a shift in approach from the initial literature search; for example, these included the feasibility of ACP in advanced dementia (Sampson et al., 2011), patient and carer needs to inform ACP (Dickinson et al., 2013; Poppe et al., 2013; Goodman et al., 2013), prevalence of ACP over time from diagnosis (Garand et al., 2011; Vandervoort et al., 2012) and carer factors that may inhibit or enhance ACP for the person with dementia (Ayalon et al., 2012; Harrison Dening et al., 2012).

A notable shift between the two searches of this review is that studies generally moved from counting ACPs or comparing to other disease groups to try and explore some of the complexities of decision making and influential factors.

2.3.6 Study Settings

A wide range of care settings were used in the studies retrieved. Nursing and care homes were the focus of ten studies (33%) (Caplan et al., 2006; Forbes et al., 2005; Lacey, 2005; Rurup et al., 2006; Triplett et al., 2008; Livingston et al., 2012; Vandervoort et al., 2012; Goodman et al., 2013; De Gendt et al., 2013; Livingston et al., 2013). Three studies (10%) involved older people's mental health teams (Fazel et al., 1999; 2000; Gregory et al., 2007). Three (10%) involved dementia supports groups (Finucane et al., 1991; Hirschman et al., 2006; 2008). Six studies (n = 6, 20%) used a memory clinic setting (Hirschman et al., 2004; Lingler et al., 2008; Garand et al., 2011; Ayalon et al., 2012; Harrison Dening et al., 2012; Poppe et al., 2013). Other settings were primary care (Cavallieri et al., 2002), a home call service to community based older people (Haydar et al., 2004), a dementia research centre (Mezey et al., 2000), a broader community setting (Karel et al., 2007), acute hospital (Sampson et al., 2011) and services for older people across UK health and social care (Dickinson et al., 2013; Robinson et al., 2013).

There was little consistency found in the research methods, aims and objectives that enabled pooling of data for review purposes. However what can be seen is that issues for advance care planning for PWD differ in respect of their point on the disease trajectory and the care setting within which they find themselves.

2.3.7 Study populations

The analysis of the papers reviewed in the first and second searches (see Table 2.4) revealed several key target populations, which can be summarised as:

- Non cognitively impaired people for comparison with other disease groups
- Family carers
- People with dementia
- Professional and paid carers

Non-cognitively impaired populations, for comparison of views with PWD, were used in five (17%) of the studies (Fazel et al., 1999; 2000; Haydar et al., 2004; Lingler et al., 2008).

Family carers were involved in almost half (n = 14, 48%) of the studies (Finucane et al., 1991; Caplan et al., 2006; Forbes et al., 2000; Mezey et al., 2000; Hirschman et al., 2004; 2006; 2008; Rurup et al., 2006; Sampson et al., 2011; Harrison Denning et al., 2012; Dickinson et al., 2013; Poppe et al., 2013; Ayalon et al., 2013; Livingston et al., 2013).

Professional and paid carers were the focus of nine (30%) of the studies (Caplan et al., 2006; Cavalieri et al., 2002; Lacey, 2005; Rurup et al., 2006; Livingston et al.,

20012; Vandervoort et al., 2012; Robinson et al., 2013; De Gendt et al., 2013). Just over half of the studies (n = 15, 52%) involved two or more of the above groups in their target populations.

A key finding is that over time, there has been more involvement of PWD in studies of this kind. The first search found that just under half of the studies considering ACP (n = 8, 48%) directly involved PWD (Finucane et al., 1991; Caplan et al., 2006; Fazel et al., 1999; 2000; Hirschman et al., 2004; Gregory et al., 2007; Karel et al., 2007; Lingler et al., 2008).

In contrast, in the second search covering the ensuing three years, eight of the 12 papers retrieved included PWD in their research (n = 8, 67%) (Garand et al., 2011; Sampson et al., 2011; Harrison Denning et al., 2012; Dickinson et al., 2013; Poppe et al., 2013; Ayalon et al., 2013; Goodman et al., 2013; Livingston et al., 2013).

Table 2.4 Study populations

Paper	People with dementia	Family carers (inc spouses)	Professional paid carers	Cognitively intact control	Review and analysis of case records
Qualitative Studies					
Forbes et al. (2000)		Carer of person with moderate to severe dementia			
Livingston et al. (2012)			Nursing home staff		
Robinson et al. (2013)			Professionals from Primary Care Trust, acute NHS hospital, Ambulance Trust, Local Authority, voluntary organisations and legal sector.		
Dickinson et al. (2013)	People with mild to moderate dementia under health or local authority care	Informal carers			
Goodman et al. (2013)	People with dementia living in care homes				
Poppe et al. (2013)	People with mild dementia attending a memory clinic and CMHT	Carers of people with dementia attending a memory clinic and CMHT	Staff members of a memory clinic and CMHT		
Quantitative Studies					
Caplan et al. (2006)	Nursing home residents	Families of resident	Care home staff and GPS's		

Paper	People with dementia	Family carers (inc spouses)	Professional paid carers	Cognitively intact control	Review and analysis of case records
Cavalieri et al. (2002)			Primary Care Physicians		
Fazel et al. (1999)	People with dementia under the care of psychogeriatric team			Elderly volunteer control from pensioners luncheon club	
Fazel et al. (2000)	People with dementia under the care of psychogeriatric team			Elderly volunteer control from pensioners luncheon club	
Gregory et al. (2007)	People with a diagnosis of Alzheimer's Disease				
Haydar et al. (2004)	People with dementia enrolled on house call programme			People with CHF enrolled on house call programme	
Lacey (2006)			Nursing home social care workers		
Lingler et al. (2008)	People with MCI and probable AD from a University memory clinic		Non dementia volunteers		
Mezey et al. (1996)		Spouses of people with dementia			
Rurup et al. (2005)		Relatives of people with dementia residents	Physicians and nurses caring for residents with dementia		
Triplett et al. (2008)					Case records of care home residents with advanced dementia

Paper	People with dementia	Family carers (inc spouses)	Professional paid carers	Cognitively intact control	Review and analysis of case records
Garand et al. (2011)	People with MCI or dementia attending an ADRC memory disorders clinic				
Vandervoort et al. (2012)			Survey of nurses and administrators of nursing homes		Retrospective analysis of care records of deceased people with dementia
Ayalon et al. (2012)	People with dementia attending a psycho-geriatric clinic	Spouses of people with dementia attending a psycho-geriatric clinic			
De Gendt et al. (2013)			Survey of nurses and administrators of nursing homes		Retrospective analysis of care records of deceased people with dementia
Mixed Methodologies					
Finucane et al. (1991)	People with dementia from an AD support group	Main carer of person with dementia			
Hirschman et al. (2004)	People with dementia attending memory clinic	Carer of person with dementia			
Hirschman et al. (2006)		Family carer of person with advanced dementia			
Hirschman et al. (2008)		Family carer of person with advanced dementia			
Karel et al. (2007)	People with mild/early dementia			Self referred elderly control	
Sampson et al. (2011)	People with advanced dementia admitted as an emergency to an acute hospital	Carers of people with advanced dementia admitted as an emergency to an acute hospital			

Paper	People with dementia	Family carers (inc spouses)	Professional paid carers	Cognitively intact control	Review and analysis of case records
Harrison Dening et al. (2012)	People with dementia attending memory clinic, CMHT or Admiral Nursing services	Carers of people with dementia attending memory clinic, CMHT or Admiral Nursing services			
Livingston et al. (2013)	Nursing home residents with dementia	Relatives of nursing home residents with dementia	Nursing home staff		

Note: CMHT = Community Mental Health Team. ADRC = Alzheimer's Disease Research Centre.

— ■ — Studies below line were retrieved during the second literature search

The target populations included the full range of cognitive impairment from mild cognitive impairment (MCI) (Lingler et al., 2008), mild dementia (Harrison Dening et al., 2012; Poppe et al., 2013), mild to moderate dementia (Cavallieri et al., 2002), moderate to severe dementia (Forbes et al., 2000) to advanced or end stage dementia (Mezey et al., 2000; Lacey, 2005; Caplan et al., 2006; Hirschman et al., 2008; Triplett et al., 2008).

Others broadly stated 'dementia' (Fazel et al., 1999; 2000; Haydar et al., 2004; Karel et al., 2007; Rurup et al., 2006). One used a consensus based diagnosis of probable Alzheimer's disease (Lingler et al., 2008). Other studies, whilst using a diagnostic framework, did not indicate explicitly their population in terms of level of cognitive impairment (Finucane et al., 1991; Gregory et al., 2007; Hirschman et al., 2004).

2.3.7.1 Representativeness of populations studied

Most studies did not include information about the ethnic and social mix of their samples. Some studies (n = 6, 21%) acknowledged this limitation (Forbes et al., 2000; Hirschman et al., 2006; 2008, Lingler et al., 2008; Triplett et al., 2008). Those studies that only provided limited or no demographic data may not reflect the target populations rendering the study less generalisable to other settings (Finucane et al., 1991; Fazel et al., 1999).

2.3.8 User and carer stakeholder involvement

Three studies employed an intervention that involved family carers, PWD and professional carers (Caplan et al., 2006; Poppe et al., 2013; Livingston et al., 2013) (Table 2.4). There was limited reporting of involvement of PWD and carers in the

study design (n = 2) (Finucane et al., 1991; Lacey, 2005). Only one study reported that they involved PWD and/or family carers in the development of the design or conduct of their study (Finucane et al., 1991) and one study reported involving professional respondents in these processes (Lacey, 2005).

2.3.9 Study quality

Study quality varied, with some studies not being explicit about the study date and duration, the process for diagnosing dementia, who conducted each stage of the research and any preparatory training for researchers involved.

Each study discussed the processes for ethical approval, recruitment and gaining consent of participants. However, of the 19 studies that involved PWD, only 12 (63%) identified the level of cognitive function using a measurement scale, for example, the MMSE (Cavallieri et al., 2002; Fazel et al., 1999; Gregory et al., 2007; Hirschman et al., 2006; Lacey, 2005; Mezey et al., 2000; Rurup et al., 2006). Only two studies in the initial search discussed reasons for attrition (Hirschman et al., 2006; Mezey et al., 2000) whereas in the second search more studies included data on attrition and reasons for this (Sampson et al., 2011; Garand et al., 2011; Ayalon et al., 2012; Harrison Denning et al., 2012; Livingston et al., 2013; Goodman et al., 2013).

The detail on inclusion and exclusion criteria was variable. In the first search three studies lacked clarity on their diagnostic criteria (Finucane et al., 1991; Haydar et al., 2004; Triplett et al., 2008) whereas all studies in the second search gave this data.

2.4 Findings of included studies

Given the heterogeneity of the various studies in terms of methodology, instruments used and outcomes, it was not possible to pool data for further analysis. I found no generic or agreed checklist to assess the quality of mixed methods studies and also consulted with the department's systematic reviewer (BC), therefore I will discuss both the merits of each paper individually and identify common themes through a process of content analysis; identifying, coding and categorising themes as they emerge from the data (Coffey and Atkinson, 1996). This involved manual coding and theming independently and then collectively by the researcher (KHD) and supervisor (ELS) to ensure reliability and validity. This process generated the following themes:

- Cognitive impairment and mental capacity for ACP
- Advance care planning and decisions about end of life care and treatment
- Prevalence of advance care planning in dementia
- Advance care planning in dementia compared with other groups
- Families and decision making
- Professional attitudes

2.4.1 Cognitive impairment and mental capacity

Three studies explored the characteristics of the person with dementia and their ability or capacity to make decisions around advance care planning (Table 2.5). Gregory et al., (2007), in a quantitative descriptive cross-sectional study in the UK, aimed to investigate if capacity to make an enduring power of attorney was significantly related to the degree of cognitive impairment and whether the MMSE was a good predictor of capacity. They concluded that an MMSE score of ≥ 18

could be used as a screening tool to help inform a clinical capacity assessment though patients should always undergo individual assessments where possible.

Hirschman et al. (2004) in a prospective observational cohort study found that a threshold MMSE <20 was an indicator of the carers' increased involvement in medical decision making. This threshold also indicated a decline in the level of (carer reported) patient involvement and increasing carer dominated decision making ([MMSE = 19-12; moderate cognitive impairment] OR = 2.35, 95% CI = 1.01-5.49; P=.048; [MMSE <12, severe cognitive impairment]: OR = 29.38, 95% CI =5.98-144.25, P=.001). They concluded that increasing age of patients with mounting carer burden were significant independent predictors of carer dominated decision making. Hirschman et al. also felt this provides clinicians with a degree of prognostic insight that can help carers understand how their role in decision making may change over the course of a patient's dementia.

In a paper using data from the original study in 1999, Fazel et al. asked one hundred elderly individuals about treatment preferences in three clinical vignettes. Fifty had a diagnosis of dementia, and 50 were volunteers. They examined the influence of cognitive impairment, pre-morbid intelligence and decision making capacity upon the completion of advance directives on treatment preferences for life sustaining medical therapy. Subjects who opted for life sustaining medical treatments when faced with end of life scenarios had lower MMSE scores (mean 22.6/30, compared to a mean score of 26.10/30 for those who would not choose a life sustaining intervention) (P<0.05, no confidence intervals were presented). Other results from this study are discussed in 2.4.4. This is likely due to the loss of the individual's ability to make decisions that require complex judgements to be made.

2.4.2 Summary

- An MMSE score of 18 to 20 or above was a useful indicator that a person with dementia would be able to engage in advance care planning discussions though this was seen as no replacement for individual clinical assessment.
- People with lower MMSE scores, when presented with hypothetical scenarios, tend to opt for life sustaining treatments.

Table 2.5 Results and main conclusions described by the main study themes: Cognitive impairment and mental capacity

Paper	Results	Conclusions
Cognitive impairment and mental capacity		
Gregory et al. (2007)	There was significant association between level of cognitive impairment and capacity to create an EPA: $\chi^2 = 35.15$ ($P = 0.0001$). MMSE score significantly predicted capacity status (OR = 1.6, 95% CI 0.863-0.979) Optimal sensitivity (86.6% CI 67.4-95.5%) and specificity (82.2% CI 67.4-91.5%) were obtained using a cut off MMSE score of 18.	The MMSE could be used as a screening tool to help inform a clinical capacity assessment in patients with Alzheimer's disease. Where direct assessment is not possible MMSE scores could be used to aid retrospective assessments of capacity to create an EPA.
Fazel et al. (2000)	Cognitively impaired older people who were incapable of completing advance directives were significantly more likely to opt for life sustaining interventions. There was no association between pre morbid intelligence and treatment preferences ($P = 0.12$).	Cognitive impairment appears to influence treatment preferences for life sustaining medical therapy. With increasing cognitive impairment, elderly individuals tend to opt for treatment interventions.
Hirschman et al. (2004)	With MMSE <20 threshold the caregivers involvement in medical decision making increased, the level of caregiver reported patient involvement declined (Moderate [MMSE = 19-12]: Odds Ratio = 2.35, 95% CI = 1.01-5.49; $P = .048$; Severe [MMSE, 12]: OR = 29.38, 95% CI =5.98-144.25, $P = .001$). Older patients with mounting caregiver burden were significant independent predictors of a caregiver dominated decision making.	Provides clinicians with prognostic information that can help caregivers understand how their role in decision making will change over the course of a patient's dementia.

Note: EPA = Enduring Power of Attorney. MMSE = Mini Mental State Examination.

2.4.3 Advance care planning and decisions about end of life care and treatment

Six studies explored advance care planning and issues of decision making around end of life care and treatments (Table 2.6). In a small study, Finucane et al. (1991) conducted semi-structured interviews with six patient-carer dyads, posing three hypothetical future severe illness scenarios, measured if such discussions were burdensome for the person with dementia. They repeated the interview schedule at three different points in time to assess consistency in response. They found that, whilst carers anticipated an adverse effect at being asked such questions, no distress was exhibited at any stage by the patients; indeed they were more likely to indicate they would refuse life sustaining therapy if they were to become more cognitively impaired. They concluded that many patients with mild or moderate dementia have capacity to be involved in discussion of plans about possible future illness and may establish useful and valid advance directives.

In a prospective quantitative study of 50 spouses of PWD, Mezey et al. (2000) found that almost equal numbers of carers would consent to or forgo cardiac resuscitation for the person with dementia. Just over half (n = 28, 56%) would forgo mechanical ventilation; just under half (n = 21, 42%) would forgo a feeding tube; five (10%) would forgo antibiotics; five (10%) would forgo all treatments and about a quarter of all participants (24%) would forgo all but antibiotics. Mezey (2000) and colleagues found that there was a greater likelihood to forgo treatments in the face of coma ($P < .001$) than critical illness ($P < .001$) and participants were also more confident in their decision in these instances. Spouses consenting to treatment were more comfortable in agreeing to life sustaining treatments than to forgo them. They found a trend for highly burdened spouses to consent to treatment, however, the investigators concluded that professionals need to provide additional support to spouses choosing to forgo rather than consent to treatments.

The second search revealed four further studies in this area. An Israeli cross sectional study (Ayalon et al., 2012) of 53 couples (person with dementia and their spouse) examined concordance for end of life care treatment preferences. As with Mezey et al. (2000) couples were presented with hypothetical scenarios, requiring a yes-no response to treatment preferences. However, in addition, Ayalon et al. asked the spouses to report their own wishes as well as predicting those of the person with dementia. Results showed moderate agreement between patients and their spouses and limited evidence for projection of the spouses' own preferences on their assumptions of patients' preferences.

In an exploratory randomised controlled trial in the UK, Sampson et al. (2011) designed and piloted a palliative care and advance care planning intervention for people with advanced dementia admitted to acute hospital care. The pilot involved a palliative care assessment which then informed ACP discussions with family carers. Carer-patient dyads were randomised to 'usual' care (n = 11) or the intervention (n = 22) arms. Whilst ACP discussions were well received, carers were difficult to recruit to the study and few patients went on to write ACPs despite intensive support from an experienced nurse specialist. The authors argued that this may have been due to underlying attitudes related to the complexity of the acute hospital environment, denial of death, the belief of 'one day at a time' or the 'impossibility' of planning for the future in this population.

Two studies explored if older PWD and their family carers are able to identify wishes and preferences for end of life care (Harrison Denning et al., 2012; Goodman et al., 2013). In a mixed method study using a modified Nominal Group Technique (Harrison Denning et al., 2012), I aimed to explore whether PWD and their carers were able to generate and prioritise preferences for end of life care and whether carers influenced the choices made by the person with dementia. Three nominal

groups were held: one with carers, one with PWD and one comprising of both. I found that wishes and preferences of PWD and their family carers may differ. To ensure those of the person with dementia are heard and respected may require discussions to be held as early in the disease as possible and offered on a one to one basis (This study is discussed fully in Chapter 3). Goodman et al. (2013) conducted exploratory 'guided conversations' with residents with dementia living in care homes to elicit their views on life in the care home, their health and thoughts for the future including wishes for end of life. Using qualitative thematic analysis they identified three linked themes; dementia and decision making, everyday relationships and place and purpose. They found that experiences of care and relationships (with relatives and care staff) were important to them now and in the future.

2.4.4 Summary

- PWD do not become distressed when discussing end of life issues.
- People with mild to moderate dementia are able to be involved in end of life care discussions and planning and can articulate what is important for them.
- Spouses of PWD are likely to be better at predicting what the person with dementia would have wished for but are reluctant in making decisions to forgo treatment on their behalf.
- Overall accuracy of carers in prediction of wishes and preferences is at best moderate.

Table 2.6 Results and main conclusions described by the main study themes: Advance care planning and decisions about end of life care and treatment

Paper	Results	Conclusions
Advance care planning and decisions about end of life care and treatment		
Finucane et al. (1991)	Patients did not show distress at being asked about discussing end of life issues and they were more likely to indicate they would refuse life sustaining therapy if they were to become more cognitively impaired.	Patients with mild or moderate dementia may be involved in discussion of plans about possible future illness.
Mezey et al. (1996)	Equal numbers of caregivers would consent to or forgo CPR. Just over half (28) would forgo a breathing machine. Just under half (21) would forgo a feeding tube. 5 would forgo antibiotics. 5 would forgo all treatments and 12 all but antibiotics. There was a greater likelihood to forgo treatments in the face of coma rather than critical illness and were more certain in this instance also. Spouses consenting to treatment were more comfortable with this decision than those to forgo. There was also a trend for highly burdened spouse to consent to treatment.	Professionals need to provide additional support to spouses choosing to forgo rather than consent to treatments.
Sampson et al. (2011)	The thirty two patients recruited were physically frail and in the advanced stages of dementia; 62% had pressure damage to the skin, all needed feeding assistance and 95% were in pain. Nearly 50% died during the six-month follow-up period. Carers were difficult to recruit during acute admission; 33 patients and carers entered the study (22 intervention arm; 11 control arm). Only seven carers made ACPs, despite intensive support from a nurse specialist.	ACP is, in theory, a necessary intervention for people with severe dementia; the reluctance of carers to write plans needs to be explored further.

Paper	Results	Conclusions
Ayalon et al. (2012)	Patients were more likely to opt for more treatment than their spouses. Moderate agreement between patients and spouses was evident for preferences regarding end of life decisions for the patients. There was little concordance between the wishes of the spouses regarding their own preferences and what they wanted for the patient or what the patient wanted. When incorrectly predicting patients' preferences, spouses were more likely to ask for treatment.	There is moderate agreement between patients and their spouses, but limited evidence for projection of spouses' preferences on patients (i.e. spouse making predictions based on own wishes). Potential differences in end-of life preferences between older adults with MCI or mild dementia and their caregivers should be taken into consideration in preparation of ACP.
Advance care planning and decisions about end of life care and treatment		
Harrison Dening et al. (2012)	Quality of care, family contact, dignity and respect were ranked as significant themes in nominal groups of carers, PWD and both carers and PWD. Transcript analysis revealed three main themes; quality of care, independence and control at end of life, raising issues of assisted dying and euthanasia.	Wishes and preferences of PWD and their family carers may differ. To ensure the wishes and preferences of PWD are respected, their views should be ascertained early in the disease before their ability to consider the future is compromised.
Goodman et al. (2013)	The impact of having dementia and participation in decision making provided key insights into care preferences. Key linked, themes were, dementia and decision making, everyday relationships and place and purpose. Accounts of everyday experiences of care, key relationships and acceptance of the care home as their home demonstrated what was important to them now and for the future.	The experience of living and dying in a care home is inextricably linked. End of life care planning and decision making could be enriched by exploring and documenting the preoccupations, key relationships and everyday care wishes of the PWD.

Note: CPR = Cardio Pulmonary Resuscitation. PWD = Person with Dementia. MCI = Mild Cognitive Impairment. ACP = Advance Care Planning. PWD = Person With Dementia.
 ■ ■ ■ Studies below line were retrieved during the second literature search

2.4.5 Prevalence of advance care planning in dementia

Four studies examined the prevalence of advance care plans in dementia (Triplett et al., 2008; Garand et al., 2011; Vandervoort et al., 2012; De Gendt et al., 2013) (Table 2.7).

In an American study, Triplett et al. (2008) undertook a prospective longitudinal study (just under 3 years) of end of life care in PWD and reviewed documentation of residents (n = 1230 from three nursing homes in the USA) with advanced dementia in the end stages of life and how they had conveyed their wishes for end of life care in advance directives. As with Lingler et al. (2008) they found that advance directives were associated with higher education and white race; however the majority of study participants were of white race (84%) so the sample was not reflective of broader populations and may not be generalisable. The study was also limited to one state of USA, and it must be noted that the laws on the requirement of advance directives vary from state to state. In their conclusion they found that certain populations required specific approaches and targeting e.g. those less educated, males and those of African American race.

In another American study, Garand et al. (2011) undertook a retrospective analysis of data that were collected prospectively to extract items pertaining to ACP in annual memory clinic interviews. The sample comprised people with a diagnosis of MCI and people with early (n = 72) and moderate to severe (n = 55) Alzheimer's disease who were interviewed annually over a five year timeframe. No advance directives were noted at baseline. ACP activity was measured by the presence of a Durable Power of Attorney (DPOA) or a living will (LW). By year five, 39% of participants had initiated an ACP with younger subjects more likely to have done so. The authors suggested that there was a need for a targeted ACP intervention to increase this. However, the sample was biased towards younger and less

cognitively impaired participants so this may have significantly affected the results and the conclusions drawn and no data were presented on mortality in the five year period and if so, whether ACPs were followed.

Two Belgian studies both used a dataset from a retrospective cross-sectional post-mortem study of nursing home residents in 2006 (Vandervoort et al., 2012; De Gendt et al., 2013). Vandervoort et al. (2012) used a structured questionnaire with the nurses who had been closely involved with deceased residents about diagnosis of dementia and documented care planning, inclusion of advance directives and GP treatment orders. The nurses identified 764 deceased residents with dementia of whom only 3% had had an advance directive and 59% a GP treatment order. The presence of a GP treatment order was associated with a lower number of deaths occurring in hospital (OR 0.38; CI, 0.21-0.70). In the second study using the same dataset, De Gendt et al. (2013) also studied the prevalence of advance directives but examined them in relation to the deceased residents' demographic and clinical characteristics and the care they had received. They sent questionnaires to nursing home administrators and nurses; though nurses provided most of the required data (95.2%). Results were similar to the first study, demonstrating that the presence of an advance directive or physician's orders were associated with higher receipt of palliative care and fewer deaths in hospital. Although there were many confounders in this study, such higher educated participants may have been more assertive in considering ACP and/or made sure they received appropriate palliative care, the authors made recommendations for a targeted intervention to increase ACP in residents with dementia.

2.4.6 Summary

- Prevalence of advance directives and advance care plans are associated with higher education and white populations.
- Whilst advance directives are associated with better palliative and end of life care outcomes this may be associated with participants generally being of higher education and thus more assertive in their demand for appropriate care and support.
- ACP processes and documents do not largely involve the person with dementia in their formulation.

Table 2.7 Results and main conclusions described by the main study themes: Prevalence of advance care planning in dementia

Paper	Results	Conclusions
Prevalence of advance care planning in dementia		
Triplett et al. (2008)	66% of sample had an advanced directive. Trend to more common in females; race (P=.002) and education (P=.037) were the only factors that were significantly associated with having an advanced directive.	More years of education and white races were significantly associated with having an advance directive. With the exception of comfort care and pain treatment, AD's were largely used to restrict many forms of end of life care.
Garand et al. (2011)	By 5 year follow-up, 39% had initiated ACP, with little difference by baseline diagnosis. Younger subjects (>65 years) were more likely to initiate advance directives (43%) than older subjects (37%). This age effect was more pronounced in men as well as in married subjects, those with a family history of dementia, those with no depressive disorder, and subjects with moderate to severe AD (versus those with MCI or early AD) at baseline.	Only a minority of subjects initiated ACP. The findings suggest the need for interventions aimed at enhancing ACP completion rates, particularly among older adults with cognitive impairment, since these individuals may have a time-limited opportunity to plan for future medical, financial, and other major life decisions.
Vandervoort et al. (2012)	In 345 nursing homes (58% response rate), nurses identified 764 deceased residents with dementia of whom 62% had some type of documented care plan, i.e. advance patient directives in 3%, a legal representative in 8%, and GP orders in 59%. Multivariate logistic regression showed that the presence of GP orders was positively associated with receiving specialist palliative care in the nursing home (OR 3.10; CI 2.07-4.65). Chances of dying in a hospital were lower if there was a GP order (OR 0.38; 0.21-0.70).	Whereas GP orders are relatively common among residents with dementia, advance patient directives and legal representative are relatively uncommon. Nursing home residents receiving palliative care are more likely to have a GP order. GP orders may affect place of death.
De Gendt et al. (2013)	Administrators of 318 NHs (53.5%) reported 1303 deaths. Nurses provided information about 1240 (95.2%) of these deaths. At the end of life, NH residents often had dementia (65.2%) and were severely dependent (76.1%). Almost half (43.1%) had at least one hospital transfer during the last three months of life and two thirds received palliative care. Half had an ACP, predominantly a physician's order and less often an advance directive. Having advance directives or physician's orders was	Prevalence of ACPs and formal authorization of a legal representative was low among the deceased NH residents in Flanders, Belgium. There was a higher prevalence of physician's orders, often established after the resident had lost capacity. Initiatives should be developed to stimulate more advance discussion on care options and making end of life decision with the residents while they retain capacity.

Paper	Results	Conclusions
	associated with receiving palliative care. Residents with a physician's order more often died in the NH. Nine percent had a legal representative.	

Note: CPR = ACP = Advance Care Planning. AD = Alzheimer's disease. MCI = Mild Cognitive Impairment. GP = General Practitioner. NH = Nursing Home.

— • — Studies below line were retrieved during the second literature search

2.4.7 Advance care planning in dementia compared with other groups

Four studies considered the decision making abilities and/or preferences of PWD compared with other groups: cognitively intact older adults (Fazel et al., 1999; 2000; Lingler et al., 2008) or other disease groups (Haydar et al., 2004).

Haydar et al. (2004), in a US study, compared the end of life care preferences of with people dementia and people with congestive heart failure (CHF). In a retrospective analysis of case records, they searched for the free text entries 'hospital'; 'admit'; and 'advance'. Related entries were reviewed for discussions relevant to advance medical planning. It was found that patients with CHF were more likely to receive active end of life care treatment whereas patients with dementia were treated palliatively. Haydar et al. (2004) argued that surrogate decision makers mostly plan for end of life care for PWD and that this may have contributed to this difference. The study highlighted the differences in the treatment focus in these care plans but offered no arguments as to what might influence each. The study also concluded that PWD were less likely than CHF patients to die in hospital; however this is an American study where the healthcare and medical insurance systems greatly differ from the UK system.

Fazel et al. (2000), in a cross sectional controlled study, conducted semi-structured interviews were conducted to examine the influence of cognitive impairment, pre-morbid intelligence and decision making capacity on treatment preferences. They compared the responses of PWD (n = 50) with cognitively intact elderly volunteers (n = 50). They concluded that cognitively impaired older people who were incapable of completing advance directives were significantly more likely to opt for life sustaining interventions. They found no association between pre-morbid intelligence and treatment preferences (P=0.12). They found that cognitive impairment

appeared to influence treatment preferences for life sustaining therapy and this tendency was greater with increasing cognitive impairment.

In a third study, Lingler et al. (2008) used a retrospective, cross-sectional study in the USA to explore the frequency and correlates of advance planning among cognitively impaired older adults attending an Alzheimer Disease Research Centre. They had an overall sample of 745; with 15% (n = 112) with a consensus based diagnosis of MCI; 74% (n = 549) probable or possible Alzheimer's disease and 11% (n = 84) non demented comparison subjects. They found that 65% of participants had an existing durable power of attorney (DPOA) and 56% had a Living Will and that advance care planning rates did not differ across diagnoses. They also concluded from descriptive analysis of demographic data that white (adjusted odds ratio = 4.75; 95% CI, 2.40-9.38), older (adjusted odds ratio = 1.05; 95% CI, 1.03-1.07) and better educated people (adjusted odds ratio = 2.06; 95% CI, 1.33-3.20) were more likely to have advance plans. Overall, they concluded that although most people with and at risk of the progressive decisional incapacity of Alzheimer's disease, are formally planning for the future, a substantial minority are not.

Advance care planning ideally includes communication about personal values. Karel et al. (2007) used a mixed method approach to compare three methods of value clarification (open ended, forced choice and rating scale) to explore potential benefits and pitfalls in advance care planning. A secondary aim was to identify which approaches, if any, were worthy of future instrument development. Karel et al. (2007) found that people with mild to moderate dementia were as able as a normal controls to respond meaningfully to values assessment questions, open ended questions, forced choice questions and naming a preferred surrogate decision maker. In comparing the three approaches they concluded that each had

strengths and drawbacks and had value in certain settings. Overall they concluded that people with mild to moderate dementia were generally as able as controls to respond meaningfully to questions about values regarding quality of life and health care decisions.

2.4.8 Summary

- There are differences in the treatment focus of advance care plans between PWD and the cognitively intact.
- A significant number of PWD do not have any form of advance care plan compared to other disease groups and the cognitively intact.
- People with mild to moderate dementia are as able as cognitively intact people to indicate preferences and wishes for future care.
- Increasing cognitive impairment influences the preference towards opting for life sustaining treatments.

Table 2.8 Results and main conclusions described by the main study themes: Advance care planning in dementia compared to other groups

Paper	Results	Conclusions
Advance care planning in dementia compared to other groups		
Fazel et al. (1999)	The approach can discriminate between elderly population and elderly population with dementia; interrater ($r = 0.95$) and re-test ($r = 0.97$) reliability. Validity was examined by relating this approach with global assessment by old age psychiatrists.	A patient centred approach to assess competence to complete advance directives can be reliably and validly used in routine clinical practice.
Haydar et al. (2004)	Do Not Resuscitate directives were given in 62% CHF patients; 91% in patients with Dementia ($P = 0.001$). Patients with CHF participated more than patients with Dementia in advance medical planning ($P = 0.001$)	In the months before death patients with CHF were more likely to have care plans directed at disease modification and treatment, whereas dementia patients were more likely to have care plans that focused on symptom relief and anticipation of dying.
Karel et al. (2007)	Comparing the three methods of value clarification; open ended; forced choice and rating scale, each had strengths and drawbacks. Each had value in certain settings.	People with dementia are generally as able as controls to respond meaningfully to questions about values regarding quality of life and health care decisions
Lingler et al. (2008)	65% had a DPOA and 56% had a LW. Planning rates did not differ across diagnoses. White; older and better educated people were more likely to have advanced plans.	Although most people with and at risk for the sustained and progressive decisional incapacity of Alzheimer's disease are formally planning for the future, a substantial minority are not.

Note: CHF = Congested Heart Failure. DPOA = Durable Power of Attorney. LW = Living Will. AD = Advance Directives.

2.4.9 Families and decision making

Five studies considered aspects of family involvement in supporting decision making. In a qualitative study, using focus groups involving family carers of people with moderate to severe dementia in residential facilities in the USA, Forbes et al. (2000) concluded that in order to make effective decisions family carers require emotional support, information and education on dementia and its trajectory, and understanding of issues around palliative and end of life care. Cavilieri et al. (2002), in their survey of 271 primary care physicians found that the majority were not providing sufficient information of advance care planning and related issues with carers (nor with PWD) and they concluded that education about advance care planning discussions was an issue for professionals involved with older people. Unfortunately the response rate of the survey was only 23% (n = 63), which may indicate that the respondents were those that were more confident in their discussions with patients and carers, so it may be difficult to draw more generalisable conclusions from this study.

Hirschman et al. (2006), tried to identify the criteria and standards that family carers use in making decisions on behalf of the person with dementia. They studied 30 primary family carers and decision makers purposively recruited equally from a specialist dementia centre and a long term care institution. Semi-structured interviews were used to examine current decision making and those decisions taken after healthcare experiences based on substituted judgment⁶ and best interests standards which related to American law and ethics to guide family decision making. Using qualitative thematic content analysis of interviews, they concluded that the interviewees did not use the substituted judgment standard when making decisions

⁶ Substituted judgment generally is a decision made by a person on behalf of a person who is incompetent and unable to decide for himself or herself. <http://definitions.uslegal.com/s/substituted-judgment-guardianship/>

but were more influenced by what they believed were in the current best interests of the person with dementia.

Hirschman et al. (2008) used a mixed method approach to examine types of future planning undertaken and the experiences of family carers (n = 30) who were decision makers of a relative diagnosed with dementia living in a specialist dementia centre or long term care institution in the USA. They reported that the majority of family carers (77%, n = 23) reported the person with dementia had some form of written advance directive. Over half of the family carers (57%, n = 17) reported previous discussions about healthcare preferences; half indicating some discussions relating to living and placement issues (50%, n = 15); and almost two thirds (60%, n = 18) had experienced some discussions about finances. A qualitative approach was used in the form of semi-structured interviews to explore the prompts and barriers to such discussions. Family carers indicated that the prompts for embarking on discussions for future care were triggered by medical events and changes to the living and financial situation of the person with dementia. The most common form of passive avoidance was the realisation of its importance when too late (63%, n = 19); over half indicated that discussions were actively avoided (53%, n = 16). Although based on findings from a small sample, these results suggest that barriers to advance planning discussions may be overcome by active intervention of professionals involved early on in the care of the person with dementia and in positive engagement of the family carers.

The second search in December 2013 revealed one study that explored the acceptability of ACP discussions with people with mild dementia and families shortly after diagnosis using the Advanced Care Planning in Early Dementia (ACP-ED) preferred priorities for care tool (Poppe et al., 2013), which provided an interview framework. They held in-depth interviews with patients (n=12) and family carers (n

= 8) following ACP discussions. Families found ACP a positive intervention that helped them to think about the future and prompted further discussion. Family carers acknowledged that they had tried to discuss ACP issues in the past but found it difficult and expressed a sense of relief that support was possible.

2.4.10 Summary

- Family carers require information and support to be able to make effective decisions on behalf of a person with dementia.
- Discussions about end of life care and wishes are generally reactive rather than proactive and often as a result of a medical emergency.
- Advance care planning discussions are often avoided with key opportunities to do so being missed.

Table 2.9 Results and main conclusions described by the main study themes: Families and decision making

Paper	Results	Conclusions
Family carers and decision making		
Forbes et al. (2000)	5 themes were identified that indicate the experience of decision making for carers of moderate to severe dementia; emotional effect, insult-to-life story, two faces of death, values and goals regarding end of life treatments and the unrecognised trajectory of dying.	For family carers to make effective decisions on behalf of a relative with advanced dementia they require emotional support , information and education on dementia and its trajectory and understand issues around palliative and end of life care
Cavalieri et al. (2002)	Response rate of 23% to postal questionnaire. Of those that responded 81% indicated they counselled their patients; most frequent (88%) being on ACP and living wills with DPOA (53%)	Physicians do not adequately discuss ADs with patients who have Alzheimer’s disease and their caregivers. More education and research needed.
Hirschman et al. (2006)	Family carers use substituted judgment (43%) and best interests (57%) in making decisions for the person with dementia. Barriers to discussions about healthcare preferences were identified as: waiting too long; avoidance; patient’s denial of dementia.	Suggests reasons why surrogate decision makers do not use the substituted judgment standard and highlights the value of interventions that would allow people with early dementia (and families) to discuss healthcare preferences.
Hirschman et al. (2008)	77% of carers reported the person with dementia had some form of written advance directive; 57% reported previous discussions about healthcare preferences; 50% indicated living and placement issues; 60% discussed finances. Barriers to discussions were realisation of its importance when too late (63%); avoidance (53%).	Suggests potential remediable strategies to address barriers to advance planning discussions.
Poppe et al. (2013)	Patients and carers found ACP a positive intervention that helped them think about the future, enabled people with dementia to make their wishes known and resulted in their feeling relieved and less worried about the future. The importance of sharing the ACP documentation between health service providers was highlighted.	ACP in early dementia may support the wider application of the intervention in memory services and CMHTs. ACP training and resources are required to enable this.

Note: ACP = Advance Care Planning. DPOA = Durable Power of Attorney. AD = Advance Directives.

— • — Studies below line were retrieved during the second literature search

2.4.11 Professional attitudes

Rurup et al. (2006) undertook an observational study to investigate the attitudes of physicians, nurses and relatives towards medical end of life decisions concerning patients with dementia. Out of 70 nursing homes approached in three regions of Holland, 39 nursing homes agreed to participate. This was part of a larger study to investigate decisions concerning artificial nutrition and hydration in patients with advanced dementia. The physician, nurse and relatives of a person with dementia in each home were involved. Professionals were asked to complete a questionnaire containing 15 statements related to end of life care decisions concerning nursing home patients with dementia; relatives were asked to consider ten statements (pilot study showed five of the 15 were too complicated or burdensome for relatives). In general all groups agreed on many aspects of end of life decision making. The influence of differences in religious beliefs, perspectives of the patient, and feelings of responsibility can lead to different attitudes towards end of life decisions between physicians, nurses and relatives. Relatives attach more importance to advance directives than physicians and have a more permissive attitude towards hastening death. However this study was unable to exclude the possibility that differences between physicians, nurses and relatives were a result of data being collected at different phases of the decision making process.

The second search revealed a study that explored professional barriers and facilitators to delivering improved end of life care for PWD in care homes (Livingston et al., 2012). Livingston et al. interviewed 58 care staff in a large Jewish care home where the residents' and the staffs' religion differed. Interviews continued until a maximum variation sample was achieved and theoretical saturation reached. Staff claimed they could recognise when the person with dementia was near death and understood the religious rituals required but frequently misunderstood religious tradition. Livingston et al. concluded that for staff to implement ACPs required

education and support about communication and discussion with PWD and families to support their implementation. To do this effectively staff needed to know about the resident's religious and cultural ideas as well as ritual practice. Demographic data of staff interviewed revealed that no respondents were of the Jewish faith although residents were.

2.4.12 Summary

- Family carers can find decision making on behalf of the person with dementia complicated and burdensome.
- There are differing attitudes towards the validity of advance care plans between professionals and family carers.
- Family carers and relatives place a greater importance on advance care plans than professionals.

Table 2.10 Results and main conclusions described by the main study themes: Professional attitudes

Paper	Results	Conclusions
Professional attitudes		
Rurup et al. (2005)	In general physicians, nurses and relatives agreed on many aspects of end of life decisions. Relatives attach more importance to ADs than physicians and had more permissive attitudes towards hastening death.	The influence of differences in religious beliefs, perspective of the patient and responsibility can lead to different attitudes towards end of life decisions.
Livingston et al. (2012)	Care staff generally felt warmly towards residents with dementia and could recognise when they were near to death, however care staff, nurses and doctors did not recognise themselves as a team and so communicated poorly with relatives about approaching death. They had concerns or were unaware of the validity of ACPs. They were aware of religious rituals around death but frequently misunderstood religious traditions.	Staff require education and support on end of life care in dementia and cultural issues around death. This would enable the implementation of ACPs. Education is required to encompass communication the complicated, unpredictable path of dementia near the time of death with the understanding for sensitivity and appropriate pace of information giving. Staff need to know about residents' religious and cultural ideas as well as ritual practice.

Note: AD = Advance Directive. ACP = Advance Care Planning. DPOA = Durable Power of Attorney. ACP = Advance Care Planning.

— ■ — Studies below line were retrieved during the second literature search

2.4.13 Education of professionals and relatives

In Australia Caplan et al. (2006) conducted a controlled evaluation of a system of educating residents, their families, staff and GPs about outcomes of dementia, advance care planning and hospital in the care home. This work was led by a specialist nurse with a significant element of the work involving the provision of information and education. Caplan et al. found that education and advanced care planning led to a reduction in emergency calls by 1% whereas in the control area calls increased by 21% ($P=0.0019$). Similarly, hospitalisation in the intervention area decreased by 22.7%, with the admissions in the control area increasing by 3.2% ($P=0.442$). Finally, they concluded that mortality decreased in the intervention area compared to that in the control area (30.4 deaths per 100 care home beds in the intervention arm versus 41.6 deaths per 100 beds in the control ($P<0.05$)).

In a small mixed methods study in the UK, Livingston et al. (2013) developed an education intervention comprising a manualised, interactive training programme. Delivered over ten sessions to care home staff, it aimed to improve end of life care for residents with dementia. They compared the documentation and implementation of advance care wishes both before and after the intervention. Livingston et al. claimed the results showed a significant increase in 'do not resuscitate' orders (14% pre, 73% post; $P<0.001$), and in dying in the care home as opposed to hospital (47% pre, 76% post; $P<0.02$), along with increased carer satisfaction with end of life care.

In an American study, Lacey (2005) surveyed social care staff on their roles and perceptions related to end of life care decision making for nursing home residents with end stage dementia. Their results indicated that whilst respondents perceived they had a high degree of involvement in advance directive discussions (97%) more than half (55%) felt their discipline did not allow them to initiate advance directive

discussions, indicating that either doctors or the multi disciplinary team were responsible for initiating such discussions. Most respondents (90%) encouraged 'do not resuscitate' decisions and identified risks associated with cardiac and pulmonary resuscitation at the point of admission. In considering end of life care, just over half (60%) indicated that they helped family carers clarify their thoughts about life sustaining treatment choices; half (50%) discussed the risks and benefits of nutrition and hydration, but only a small number (11%) addressed the risk and benefits of antibiotics. Most respondents (91%) felt decision making was easier when a resident had a family carer who was the designated decision maker or health care proxy. Lacey (2005) concluded that there was a need for continuing education in end of life care issues for social care staff in nursing homes, though many deal with ethical dilemmas, many are uncomfortable with withholding or withdrawing treatment for PWD.

In two recent studies from the same group, Robinson et al. (2013) and Dickinson et al. (2013) aimed to explore stakeholders' understanding and experiences of ACP. Robinson et al. (2013) conducted focus groups and individual interviews with 95 professionals from both health and social care settings in the North East of England. In this qualitative study, they aimed to explore professionals' experiences of implementing ACP in two clinical specialities: dementia and palliative care. They found that whilst professionals agreed ACP was a good idea in theory, there were significant challenges to its implementation. Uncertainty was felt throughout a number of areas: the value of ACPs and their legal status; whether current service provision could meet patients' wishes and, as with Lacey (2005), about their own, individual roles and responsibilities towards ACP development. Robinson et al. (2013) concluded that professional training is required to target these specific areas.

De Vleminck et al. (2014) found similar barriers to initiating ACP in dementia as well as other conditions; such as lack of knowledge of prognosis and terminal phases, when to initiate discussions and advance care planning processes

In a smaller qualitative study, Dickinson et al. (2013) interviewed 17 PWD and 29 family carers to investigate their views about planning for their future generally and ACP specifically. They found that most planned generally for practical, personal and financial/legal issues but did not make formal advance care plans for health. Various barriers were identified that included: uncertainty due to lack of knowledge and awareness of ACPs, finding the right time, making informal plans other than formal documentation, constraints around future choices and lack of support to make ACP and related decisions. In their conclusion Dickinson et al. identified a place for health and care staff in supporting ACP, suggesting there is a need for education and information for professionals in how best to support ACP and give families the right information and knowledge to support their decisions.

2.4.14 Summary

- Advance care planning can lead to fewer hospital admissions.
- Advance care planning can lead to greater carer satisfaction with end of life care for the person with dementia.
- Health and social care professionals require more education and training on the use and development of advance care plans.
- There remains a high degree of uncertainty amongst professionals about the validity and implementation of advance care plans.

Table 2.11 Results and main conclusions described by the main study themes: Education of professionals and relatives

Paper	Results	Conclusions
Education of professionals and relatives		
Caplan et al. (2006)	Emergency calls to the ambulance service from intervention nursing homes decreased ($P = 0.0019$). The risk of a resident being in an intervention hospital bed for a day compared with a control hospital fell by 25% ($P = 0.0001$). No significant change in mortality in intervention homes but in control rose to 11.2 per 100 beds higher than the intervention home in the third year ($P, 0.05$).	The intervention of a Clinical Nurse Specialist to promote an educational programme and an ACP framework into residential settings can reduce inappropriate hospital admissions and mortality of nursing home residents over time.
Lacey (2006)	High degree of involvement in advance directive discussions (97%); problems in the implementation of advance directives on admission; 90% encouraged DNR decisions; about 60% helped family carers clarify their thoughts about life sustaining treatment choices; about 50% discussed risks benefits of nutrition and hydration; only 11% addressed risk benefits of antibiotics; 91% felt decision making easier when resident had a health care proxy; 90% identified risks with CPR.	There is a need for continuing education in end of life care issues for nursing home staff. Discussions on admission should be followed up later when people are more emotionally prepared to discuss palliative care. Many social care staff deal with ethical dilemmas though many are uncomfortable with withholding or withdrawing treatment for people with dementia.
Livingston et al. (2013)	Post-intervention showed increases in documented advance care wishes arising from residents' and relatives' discussions about end of life; including DNR (14% pre: 73% post, $P < 0.001$); dying in the care home as opposed to hospital (47% pre: 76% post, $P < 0.02$). Relatives overall satisfaction increased from 7.5 (SD = 1.3) to 9 (SD = 2.4) $t = 17.6$, $P = 0.06$.	The authors claim this small non-randomized study is the first end of life care in dementia intervention to report an increase in family satisfaction with a reduction in hospital deaths. Results are promising but require further evaluation in diverse care homes.
Robinson et al. (2013)	Fourteen focus groups and 18 interviews were held with 95 professionals. All agreed that ACP was good in theory, implementation in practice presented challenges. There was uncertainty about their value, meeting preferences in the current service provision, legal aspects and their individual role and responsibilities. When to initiate ACP discussions was an added challenge.	The study identified professional, organisational and legal factors that can influence ACP implementation; professional training should target these specific areas. Authors called for a standardisation of ACP documentation and greater clarity on roles and responsibilities of different professional groups with more complex ACP being better carried out by experts in different disease trajectories.

Paper	Results	Conclusions
Dickinson et al. (2013)	People with dementia and their families make a number of plans for the future; practical, personal, financial and legal. However, no formal ACP (apart from appointees for financial affairs). Barriers were evidenced; lack of knowledge, finding the right time, formal or informal plans, constraints around choices and lack of support.	Health and social care professionals have a place to build on preferences by exploring underlying assumptions. They also have a role for in highlighting the aspects of ACP that are most relevant to individuals.

Notes: ACP: Advance Care Plan. DNR = Do Not Resuscitate. ACP = Advance Care Planning.

— • — Studies below line were retrieved during the second literature search

2.5 Discussion

The key findings of both searches undertaken in this review (March 2010 and December 2013) are now discussed. Despite a marked increase in the number of papers over the period between the first and second searches, the literature in this field remains small. Studies employed a wide range of approaches, settings and methods that made it difficult to pool findings from which to draw meaningful conclusions. Moreover, there is currently no generic or agreed checklist to assess the quality of studies in reviews of mixed methods. However consistent themes did emerge from the studies reviewed from both the first and second searches undertaken and the merits of each study will be discussed in the emergent themes:

- Cognitive impairment and capacity
- Advance care planning and decisions about end of life care and treatments
- Advance care planning in dementia compared with other groups
- Prevalence of advance care planning in dementia
- Families and decision making
- Professional attitudes
- Education of professionals and relatives

2.5.1 Cognitive impairment and mental capacity

A measure of cognitive functioning is the usual gauge by which most clinicians determine the severity of dementia. The Mini Mental State Examination (MMSE) (Folstein et al., 1975) is the most commonly used tool to assess cognitive functioning in the clinical setting. Since making decisions about future care choices requires a range of cognitive abilities, assessment using such a measure may be useful. However a

person would also need to have the language and capacity to understand the issues involved and to articulate choices made.

Several studies demonstrated that lower scores on the MMSE were associated with loss of capacity to take decisions and an increasing tendency for carers to take over with making choices on their behalf (Fazel et al., 1999; Hirschman et al., 2004; Gregory et al., 2007).

However, while a cognitive assessment using the MMSE acts as a useful adjunct to the examination of decision making capacity, care must be taken not to regard it as a decision tool or as a substitute for asking direct questions to assess the person's understanding of the issues involved in advance care planning. Also whilst no national data is currently collected on the baseline MMSE scores of people at first presentation to memory assessment services, there is evidence from UK studies that suggest that by this point many have MMSE scores that are already below the threshold scores that Gregory et al. (2007) and Fazel et al., (1999) have identified (Banerjee, 2007). Using an MMSE threshold may add no value to the individual clinical assessments already undertaken and is also not in keeping with the principles of determining capacity in the Mental Capacity Act 2005. The MMSE is a widely used cognitive screening tool often used before a fuller clinical assessment for the diagnosis of dementia, but it does not take into account other cognitive domains that are necessary to consider advance care planning, i.e. frontal lobe executive function, visuo-spatial skills and complex language skills.

A 'window of opportunity' is argued as a time between receiving the diagnosis of dementia and at the point a person no longer has the capacity to make decisions about

their end of life care (Thomas and Lobo 2011). However, studies reviewed here are less certain that the 'window of opportunity' presents itself in early dementia or if indeed if it ever does. The numbers of PWD in the UK who have made advance care plans or advance directives is unknown, though recent studies demonstrate a willingness on the part of PWD [and their families] to engage (Poppe et al., 2013; Goodman et al., 2013). It may be likely that many PWD fail to make an ACP as the 'window of opportunity' when they have the capacity to undertake such a process is already closed by the time they present themselves for diagnosis.

2.5.2 Advance care planning and decisions about end of life care and treatment

Advance directives and advance care planning are a relatively recent introduction in the UK, as the first literature search affirmed. However, the second search revealed an increase in the number of studies exploring issues around ACP (Figure 2.2). ACPs originated predominantly from the USA; whilst some American studies report that many PWD had some form of written advance directive (Hirschman et al., 2008), this is likely to have been seen as an outcome of the implementation of the Patient Self Determination Act (PSDA) during the 1990s (Ulrich, 2001). Whilst the PSDA has shown evidence of increasing the number of ACPs in dementia it is not generally understood if they truly reflect the preferences of the person with dementia or indeed, have an impact in effecting the persons wishes to be met at the end of life. It could also be argued that the development of the PSDA was financially driven by the medical insurance system requirements.

More recently the potential for advance care planning to contribute to better end of life care has been promoted in the End of Life Care Strategy for England (DH, 2008).

Some of the more recent UK studies, although examining different points in the trajectory of dementia, aimed to pilot specific interventions to promote ACP (Sampson et al., 2011; Poppe et al., 2013; Livingston et al., 2013).

These studies underline the complex decisions that may have to be made in ACP and end of life care and treatment. They also show how carers can struggle and importantly they also indicate that PWD and their carers have rather different perspectives.

However, carer attitudes may influence the likelihood for PWD being exposed to aggressive treatments at end of life. Mezey et al. (2000) found that those carers with a greater sense of burden were more likely to consent to life sustaining treatment. This may seem counter intuitive but Schenker et al. (2012) note that carers struggle to reconcile personal emotional needs with those of the person they care, struggling to make decisions based on what they think the person [with dementia] would have wanted. When end of life care treatment decisions are sought it is perhaps not surprising carers find themselves faced with decisional dilemmas.

Ayalon et al. (2012) examined agreement in 53 spouses for treatment decisions and found that when carers failed to accurately predict the wishes of the person with dementia, they were more likely to ask for treatment. However, participants in Ayalon's study were of one culture and religion; Israeli Jews. Cultural and religious perspectives may influence how we approach end of life care decision making through personal knowledge and experiences of death and dying (Braun et al. 1999) (discussed further in 2.5.6). In my study (Harrison Denning et al., 2012), I found that, when interviewed

together, carers often spoke over the person with dementia or negated their views (see Chapter three).

Mezey et al. (2000), Harrison Denning et al. (2012) and Ayalon et al. (2013) all highlight potential complexities around proxy decision making in the absence of any clear advance directive from the person with dementia. As Sampson et al. (2011) have indicated, carers find it difficult to engage in decision making at times of crisis or at times when there are significant stressors. It may be that carers do not make the choices that are in the best interests of the person with dementia or their decisions may indirectly reflect their own views on preferences and wishes for their end of life care.

Further exploration of dyad populations (both the person with dementia and their family carer) is required. Examination of preferences for future care and disagreements between the person with dementia and the carer may be helpful in eliciting areas of agreement or non agreement of views between the two and in determining what factors influence this, e.g. challenging behaviour, carer stress, etc. Balancing the needs of both the person with dementia and their family carer(s) may be a particular challenge when advance care plans may promote one person's wishes and preferences over those of another.

2.5.3 Advance care planning in dementia compared with other groups

When considering the needs of a specific group of people, in this case PWD, it may be valuable to make comparisons with other groups of patients where the evidence base in relation to ACP is greater. The literature revealed several conflicting findings related to advance care planning when comparing dementia to other groups.

For example, Lingler et al. (2008) found no differences in advance care planning comprising people with and without dementia (see section 2.4.4). However both Lingler et al. (2008) and Triplett et al. (2008) found that white, better educated subjects across all groups were more likely to have an advanced care plan, regardless of diagnosis. In contrast, Haydar et al. (2004) found two differences in approaches documented in care plans for cognitively intact older people with CHF and those with dementia; a) a palliative rather than therapeutic approach to care was adopted for PWD and b), PWD were less likely to die in hospital. Interestingly, in the UK, these same outcomes are espoused as desired outcomes in end of life care in dementia (Sampson & Harrison Dening, 2013).

Haydar and colleagues noted that, whereas patients with CHF usually make decisions for themselves, most end of life care planning for PWD is made by surrogate decision makers and this may have contributed to the differences. But as we have already noted in Mezey's study (2000), burdened carers and proxies tend to decide on life sustaining options when faced with these difficult decisions so this may not reflect what the person with dementia would have wanted.

As well as the issue as to whether PWD are capable of making an ACP, there are also conflicting findings as to the sort of choices they make. For example, Fazel et al. (2000) reported that PWD were more likely to make decisions that were impulsive or opt for life sustaining interventions than for comfort care. In contrast Finucane et al. (1991) found that PWD were more likely to refuse life sustaining therapy as they become more cognitively impaired. The reliability of end of life care decisions made by PWD and their stability over time remains unknown.

In summary, the main difference between ACP in dementia and other conditions appears to be greater involvement of surrogate decision makers. It appears that this does have consequences for the types of end of life interventions specified, at least in some cases.

2.5.4 Prevalence of advance care planning in dementia

Researchers have focused their understanding of the issues of ACP in relation to dementia from different perspectives. As well as making comparisons in the prevalence compared to other disease groups, some have sought to examine the prevalence of ACPs in dementia alone (Garand et al., 2011; Vandervoort et al., 2012; De Gendt et al., 2013). The two Belgian studies (Vandervoort et al., 2012; De Gendt et al., 2013) both used a dataset from a national Belgian survey of 1303 deaths in 345 nursing homes. In each study nurses were asked to complete a questionnaire about the records for their deceased residents with dementia and about any documented evidence of ACP or physicians' orders. Both studies reported ACP activity was largely in the form of physicians' orders and that where these were present they correlated with lower rates of hospital deaths and greater access to palliative care support in the nursing home. In such instances the doctor has in effect become the lead decision maker, so therefore it may be more straightforward for nursing staff to follow 'orders' rather than engage families in the process of ACP.

Garand et al. (2011) found that younger subjects were more likely to initiate an ACP but that older PWD and their families required targeted support. This suggests that ACP for older groups perhaps requires specific attention for it to become a helpful and meaningful process.

Advance care planning is a relatively new concept in health and social care in the UK, especially for PWD, so it is not surprising that there is little evidence concerning the existence and effectiveness of ACP's.

2.5.5 Family carers and decision making

Advance directives and ACPs are a means of extending the autonomy of the 'patient' to situations when they are no longer competent to make decisions regarding their care. When older PWD are deemed no longer able to make decisions about their care and treatment, family carers are often called upon to do so. Concern for family carers may be a key motivation for older people to undertake an ACP, as it may be seen as a way of reducing the burden that families may face in having to make decisions at the end of life.

The burdensome effects of the illness such as feelings of guilt, a sense of failure when the person with dementia goes into long term care and a lack of information on the disease trajectory and its prognosis, may leave family carers unprepared to make effective decisions on end of life care on behalf of a relative with advanced dementia (Forbes et al., 2000). Several authors concluded that family carers require emotional support, information and education on dementia and its trajectory and a better understanding of issues around palliative and end of life care (Forbes et al., 2000; Poppe et al., 2013; Robinson et al., 2013; Dickinson et al., 2013) to achieve better advance care planning.

However, preparation of family carers in the form of information and prognosis giving may not in itself be sufficient. In making decisions about the person with dementia, family carers may experience conflicting motivations between what they believe them to

have wanted or what may be in their best interests, and they struggle to understand or predict the person's wishes or what they might have been. For example, Ayalon et al. (2013) found only moderate agreement in spouses' ability to predict the person's wishes. When they were unable to predict they were more likely to ask for treatment. Ayalon and colleagues' view was that spouses did not project their own preferences but truly predicted those of the person with dementia, but this conflicts with evidence that projection does occur in the general population (Fagerlin et al., 2001).

To be fair to carers, it is difficult to see how they would not be influenced by their own experience and their own priorities and wishes for future care. Thus any decision is likely to reflect a mixture of their consideration of the person with dementia's views and their own perspectives.

Professionals either avoid having discussions with family carers about future healthcare preferences or they wait too long. This means that the person with dementia is no longer involved because of lack of capacity, or that such discussions are only embarked upon at times of crisis (Hirschman et al., 2008). Sampson et al. (2011) found that carers were reluctant to engage in advance care planning for their relative with advanced dementia during an acute hospital admission. Discussions on planning for future care are probably best done early on in the disease trajectory and in anticipation of events rather than in a crisis, for example, whether to use artificial nutrition and hydration. Interventions that would allow carers and families to discuss future healthcare preferences may be valuable (Forbes, et al, 2000; Hirschman et al., 2008). Ideally the views of PWD and their carers should be sought, not only collectively but also separately to elicit convergent or divergent views that could influence advance care planning.

Professionals and family carers may anticipate an adverse reaction to pursuing ACP with the person with dementia but this is not necessarily the case. For example, Finucane et al. (1991) found that whilst family carers anticipated distress those concerns were unfounded with no evidence of distress in the person with dementia. Whilst the study sample was small, Finucane et al. found that no distress was evident in the person with dementia before or after the discussions were held. Carers felt that the person they cared would feel *'upset'* if doctors were to hold discussions about advance care planning, whereas patients thought *'it would be a good idea....to talk...today about this subject'*. This study indicates the potential for differences between the views of the person experiencing dementia and their family carer when considering end of life preferences for care. Similarly Poppe et al. (2013) found that participants in their study found talking about ACPs was a relief and made them feel less worried about the future.

It is not clear to what extent family groups engage in shared decision making historically, before the onset of dementia, so it is not surprising that carers find it difficult to cope in the event of what is often a medical or social crisis, even in the early stages of dementia.

2.5.6 Professional attitudes

As mentioned in the previous section, there are concerns about the timeliness and initiation of advance care planning discussions (Duke & Thompson, 2007; Horne et al., 2007) and also about the adequacy of professionals' knowledge and skills in advising on issues related to developing advance care plans (Seymour et al., 2010).

Physicians, nurses and relatives may have differing perspectives regarding medical decisions at the end of life. Differences in religious beliefs, perspective of the patient and care responsibilities may lead to differences in attitudes between physicians, nurses and relatives (Rurup et al., 2006). Where advance directives do exist, relatives seem to attach great importance to them and believe they *have* to be followed, whereas physicians know that only certain types of advance directives have any legal standing and that in other situations legally their decisions are guided by the '*best interests*' of the patient (Rurup et al., 2006). Attitudes may differ not only between different groups of people but also between different cultures and countries.

Physicians often do not adequately prepare neither the person with dementia nor their carer for future care issues and related decisions (Cavallieri et al., 2002). Cavallieri's survey of physicians yielded such a low response (23%) that arguably only the more motivated physicians or those more active in advance care planning responded. Even so, one fifth of these did not engage in advance care planning discussions at all. Physicians failed to advise on important carer issues such as current living arrangements, end of life care, and helping carers to feel more comfortable in contributing to end of life decisions.

Other studies (e.g. Livingston et al., 2012) have found that although professionals are fairly good at recognising when a person with dementia is close to death, they are often poor at communicating this to relatives. This suggests that education is required on various issues, such as communication about the complicated and unpredictable path of dementia near the time of death and knowledge of the related carer issues.

Thus, the key professional barriers towards advance care planning identified in this review are lack of knowledge of advance care planning, failure to discuss prognostic issues of dementia with the patient and/or carer and avoidance of such discussions at a time when the person with the diagnosis of dementia has the cognition and capacity to engage. Clearly professionals are key to initiating timely and informed discussions about planning for future care with both the person with dementia and their carer, and ways to improve this need to be sought.

2.5.7 Education of professionals and relatives

As we have seen, there is a need for improved knowledge and skills (Cavallieri et al., 2002), but also for clearer policy to direct clinicians in supporting the development of advance care plans (Chang et al., 2009). There is often an expectation placed upon professionals to take a lead in initiating discussions about end of life issues. Many feel uncomfortable and unprepared for the ethical dilemmas that arise, particularly discussions about withholding or withdrawing treatment for PWD (Lacey, 2005).

Targeted end of life care education and a supportive advance care planning programme for both relatives and professionals can reduce unnecessary hospital admission and can reduce mortality of care home residents (Caplan et al., 2006). Information and education is required on many aspects of end of life care in dementia. These include understanding the physical and psychological changes that occur and the need to encourage people to start thinking at an early stage about what their wishes might be.

Professionals' concerns around engaging people in planning ahead to include assessment, management of physical and behavioural symptoms, and communicating on these difficult issues with PWD and their family carers present a challenge (Lacey, 2005). Health and social care staff delivering care for PWD often find themselves in the position of being required to initiate and undertake these very difficult discussions. Initiating such discussions is clearly a challenge to most professionals and care staff, the provision of specific education that supports the development of competencies in advanced communication may to enable them to feel more confident.

2.5.8 Size and quality of the evidence base

This field of research has grown significantly in recent years, as evidenced by trends in publications (Figure 2.2). The low yield of studies in the first search up to 2010 involving PWD in advance care planning for future health and social care is noteworthy. Over the ensuing three years up to the search in December 2013, the number of studies published almost doubled. Of all the 29 papers reviewed, only just over half (55%) of the studies actually involved PWD in the development stage of their studies or as research participants and half of these appeared after 2010 (Caplan et al., 2006; Fazel et al., 1999, 2000; Finucane et al., 1991; Gregory et al., 2007; Hirschman et al., 2004; Karel et al., 2007; Lingler et al., 2008). Only one interventional study in the first search evaluated an educational program about advance care planning and supporting their articulation (Caplan et al., 2006), whereas the second search revealed two intervention studies: one that evaluated a palliative care assessment and specialist nurse to support ACP in acute hospital care for people with advanced dementia (Sampson et al., 2011) and a manualised ten-session training program for care home staff on end of life care in dementia (Livingston et al., 2013).

Only four studies examined dyad populations including people with mild cognitive impairment (MCI) (Lingler et al., 2008); MCI and mild dementia (Ayalon et al., 2012), mild dementia (Harrison Dening et al., 2012), mild to moderate dementia (Cavallieri et al., 2002) and their respective carers. As advanced care planning in dementia also has implications for the carer; this needs further attention.

There are considerable limitations in those studies that have been published. The samples were often not well defined and it was often unclear which groups had been excluded. Most studies failed to fully define their populations; those that did were largely North American studies and these showed bias towards educated, middle class, white people. Two studies from the second search did include data on participants from a broader range of ethnic groups and backgrounds (Sampson et al., 2011; Harrison Dening et al., 2012), but even so we can draw few inferences about the UK population in general.

Overall there was very little prospective work, little in the way of evaluating interventions to improve matters and little that explores the acceptability and feasibility of advance planning in dementia. There were no prospective cohort studies that used advance planning as an intervention and examined uptake of ACP. As a result, we lack a sound evidence base as to whether the wishes and priorities of PWD are actually respected in practice, or indeed where advance care planning is a feasible and acceptable option for people with early dementia.

2.5.9 Gaps in the literature

The yield of original research papers in both searches was small which makes it difficult to derive firm conclusions about the evidence base for advance care planning in

dementia. There is an emergent pattern of factors that may influence the uptake of advance care planning, such as those that relate to patient and family, professionals and those that relate to the system within which advance care planning could take place. However, there remain significant gaps in the research in respect of this field. Perhaps the most striking omission is the lack of information directly from PWD. There are no studies observing the consistency of people's views about advance care planning as their condition advances and they approach some of the difficult choices that lie ahead.

As noted previously, there is little evidence on the compatibility of the priorities and wishes of both the family carer and the person with dementia and if these change, converging or diverging over time. Such evidence as exists suggests that these perspectives may diverge significantly. We do not yet know what factors influence agreement or divergence of views, or how these issues are handled in real life.

In the UK (in contrast to the USA where ACP is required by medical insurance) there are no data to estimate the prevalence of advance care plans among PWD. If the government's aim is for all people to have an advance care plan (DH, 2008), then their acceptability and feasibility for people with early dementia is very important for the dementia research agenda. Research should focus specifically on advance care planning for people in the early stages of dementia where arguably the 'window of opportunity' exists for this to be a truly meaningful process.

2.5.10 Methodological limits to this review

Limits to this literature review were manifest very early on by the apparent absence of literature involving PWD. In response to this small literature, the search was

broadened. Family carers and professionals involved in advance care planning in any care setting were also included to broaden the yield as much as possible. We excluded papers from our review that were not published in English so we may have missed other international studies. Although the literature was small there was a broad range of methodologies employed so it is difficult to combine the data or to draw any clear inferences. These issues were not resolved following the second search; whilst the yield almost doubled the number of papers included, the broad range of methodologies remained a significant feature.

However, there is much I have gained from studying the methods employed in this review to guide my own research. Advance care planning, and the complex factors involved, may require a mixed methods approach to achieve a better understanding of the research questions that mono-method designs may be unable to fully explore. Creswell (2009) and Creswell and Plano Clark (2011) both discuss their differences, proposing that in a quantitative study the researcher starts with a problem statement, moving on to the hypothesis or null hypothesis, through the instrumentation into a discussion of data collection, population, and data analysis. Therefore in my doctoral research I want to employ a mixed methods approach, combining a quantitative study with qualitative elements to obtain more detailed and specific information to enable a social contextualisation of the issues researched.

2.5.11 Implications for practice

Despite the End of Life Care strategy (DH, 2008), we have little evidence to indicate the feasibility or acceptability of advance care plans for PWD and their families. This literature review has highlighted the limited evidence base in this area and indicated

some significant gaps in evidence on advance care planning in dementia, particularly that which focuses on the articulation of future priorities and wishes of the person with dementia while they still have the language, cognition and judgement to do so.

ACP may never be free from uncertainties such as how and when a person may die and the preferences of that person under those circumstances. However, if decisions about care are based on the recorded wishes of the person with dementia it may be easier for family carers and professionals to act with greater confidence. The new provision of Lasting Power of Attorney for Personal Welfare introduced by the Mental Capacity Act 2005 presents an opportunity for older people to make their wishes known in advance. However, there is still no organised collection of data in respect of this.

When a person receives a diagnosis of dementia, they may become increasingly dependent upon their families to support their wishes and priorities for care. Although ACP may be based upon the wishes of the person with dementia, there may be times when these are in conflict with the carers' own wishes and priorities. We found some evidence of ACP reducing inappropriate hospital admissions and postponing mortality in PWD (Caplan et al., 2006), but further longitudinal research is required to observe influences and changes to such plans over time, levels of convergence or divergence in agreement between carers and PWD and whether ACP actually improves end of life care for this group of people.

As Admiral Nurses support the *whole family* through the disease trajectory of dementia, a key aspect of their work is to facilitate planning ahead and supporting decision making. Future planning needs to be done in the context of the patient/family relationship since the wishes and preferences of either party may be in conflict with

those of the other, studying patient-carer dyads and the complexities of such decisions is really important.

2.5.12 Recommendations for future research

As I have suggested in the previous section, further research to observe the factors leading to agreement or non-agreement between PWD and their family carers is needed. Further exploration of the ability of a person with early dementia to engage in and be supported with advance care planning is required. As advance care planning can range from a simple expression of values and preferences to the development of an advance decision to refuse treatment, we need to ensure that we can hear the voice of the person with dementia as much as possible. It is likely that the choices that they make will interact with the wishes and preferences of their relatives and carers. In some cases, they may directly conflict with each other. We need to understand more about how these conflicts arise, how they can be resolved, and how to put this knowledge into practice. When the person with dementia has lost capacity, professionals often expect carers to inform us as to what their choices might have been. Are we expecting too much of family carers in some situations or, indeed, can we be certain of their accuracy?

In summary, the main aspects of advance care planning for PWD which require further research are:

- The feasibility and acceptability of advance care planning in early dementia
- The feasibility and acceptability of advance care planning for carers of PWD
- To explore whether the preferences and wishes of the person with dementia and their family carer are compatible and, if there is a conflict, how to resolve it

- To explore whether carers can accurately predict the wishes and preferences of the person with dementia
- To consider what factors influence the accuracy of carers' predictions
- To consider what factors influence the decisions made by a person with dementia

The current evidence base for advanced care planning in early dementia is very limited. Since government policy recommends that all people should engage in advance care planning, more evidence is needed to understand the feasibility and acceptability of advance care planning in early dementia and whether carers can accurately predict the choices people with dementia would make for themselves. However, the findings of this systematic review will be considered fully within the conclusion to the entire thesis (Chapter 7).

CHAPTER 3

**PHASE ONE - PREFERENCES FOR END OF
LIFECARE: A NOMINAL GROUP STUDY OF
PEOPLE WITH DEMENTIA AND THEIR FAMILY
CARERS**

3.1 Introduction

In Chapter One I identified that advance care planning in dementia is less than straightforward; as dementia progresses, the ability to consider future thoughts and actions becomes compromised, thus affecting a person's decision making abilities. Family carers find themselves increasingly in a position whereby they are called to inform, or directly make, decisions on behalf of the person with dementia. When capacity is lost and the wishes and preferences of a person with dementia have not been previously articulated, it is often assumed the family know what their decisions might have been. There is some literature on the complexity of proxy decision making by families in older populations but very little where dementia is involved.

In Chapter Two, I concluded from my review that the current evidence base for advanced care planning in dementia is very limited. Since government policy recommends that all people should engage in advance care planning, more evidence is needed to understand the feasibility and acceptability of advance care planning in dementia and whether carers can accurately predict the choices PWD would make for themselves. It remains unknown whether the decisions that carers make accurately reflect those the person with dementia would themselves have made, or how carers are influenced by their own wishes and experiences.

3.2 Aims

The overall aim of my research is to explore whether family carers can accurately predict⁷ the wishes and preferences of the person with dementia for end of life care, and the factors that might influence this.

This chapter discusses the first phase of my research⁸; to explore whether PWD and their carers are able to generate and prioritise preferences for end of life care and to examine to what extent carers influence the choices made by PWD.

3.3 Objectives

1. To examine how PWD define their wishes and preferences for their end of life care
2. To examine how family carers define preferences for their own end of life care
3. To explore the interaction between PWD and their carers when discussing future care preferences

3.4 Exploratory question

Can PWD and family carers identify their wishes and priorities for future care?

⁷Predict' is the term I will use in this thesis to mean a family carers ability to tell us about the preferences of the person with dementia in relation to end of life care by means of their knowledge of that person.

⁸ See publication Appendix 4: Harrison Denning, K., Jones, L. and Sampson, E.L. (2012) Preferences for end-of-life care: A nominal group study of people with dementia and their family carers. *Palliative Medicine*. 27 (5), 407-417.

3.5 Method

3.5.1 Design

This phase employed both the qualitative and quantitative elements of a nominal group technique⁹ (NGT) with carers and PWD.

3.5.2 Rationale for using the nominal group technique

The NGT is a structured evaluative methodology, which was developed as a way of facilitating group or team decision making. It was first developed by Delbecq and Van de Ven (1971) as an organisational planning tool. In healthcare settings its use has largely been in the evaluation of education and in problem identification and problem solving in consumer groups (Fattah et al., 2014; Horton, 1980).

NGT is a group to facilitate decision-making which allows a rich generation of original ideas, balanced participation of all members of the group, and a rank-ordered set of decisions based on a mathematical voting method. NGT combines both qualitative and quantitative data collection in small groups of participants and involves a facilitated process to stimulate individual generation of ideas by group members, discussion and recording of these themes and finally, ranking them in order of priority.

There were several reasons why I chose to use a NGT in this phase. Firstly, it has a highly structured format which involves no in-depth preliminary discussion, yet it allows an opportunity to achieve a substantial amount of work and focus on detail in a

⁹ The nominal group technique (NGT) is a group process involving problem identification, solution generation, and decision making (Delbecq and Van de Ven, 1971).

relatively short time span (Delbecq and Van De Ven, 1971). The structured nature of the process and how it affords each person's views to be represented and valued was felt to be valuable for PWD, whilst it could also deal with the possible problem of short attention spans. Thus a single meeting of short duration for each of the three groups was felt to be of tolerable length for the participants with dementia and also offered a 'one off' approach to data collection.

Another important characteristic of the NGT process is its democratic style. One of the main criticisms of group work, particularly focus groups, is that there may be difficulties experienced with dominant group members which can distort the functioning of a group (Gallagher et al., 1993; Krueger and Casey, 2000). The NGT process affords equity of contribution through its stepped approach and its managed facilitation to allow all contributions to have value and be heard (Frankel, 1987). However I wanted to explore the effect of both the carer and the person with dementia being present together in one of the groups. This was to examine whether there was any 'carer influence' and if this affected the openness of discussions and contributions offered by the person with dementia (see objective 3).

The NGT process also provides a carefully managed avoidance of undue researcher influence and interpretation. Although the aim of the nominal groups was to seek and understand the future wishes and priorities of PWD and their carers for end of life care, the researcher was acutely conscious of the practical and conceptual difficulties in ensuring that the outcomes purely reflected those of the participants and were not dominated by researcher-led concerns. Gallagher et al. (1993) stated that researcher influence is often a problem in research that requires a qualitative understanding of the

concerns and priorities of a distinct group. A qualitative understanding of the priorities of each individual participant was essential to determining an overall view.

3.5.3 Ethical considerations

The study protocol was developed following a process that included both peer and carer [expert by experience] review. Full ethical approval was granted through the North London Local Research Ethics Committee (REC) (09/H0723/2) on 24th February 2009 (Appendix 5).

The main ethical issues addressed by the committee are discussed in the relevant sections as indicated below, but in summary included:

1. Concern was expressed that 2 hours participation in the nominal groups may be too much for people with mild dementia and also their carers. The researcher indicated that a maximum of 90 minutes would be spent in the NGT process (section 3.5.).
2. The committee sought clarification regarding the necessity to contact the GP. The researcher assured the committee that this was standard practice in clinical research and reassured them that GP medical records would not be accessed (section 3.4.10.).

The final project was registered with Barnet, Enfield and Haringey (BEH) Mental Health NHS Trust Research and Development (R&D) department. I was employed by BEH

Mental Health NHS Trust during phase one of my research which allowed me access to potential participants from the target population.

3.5.4 Study location

The Borough of Haringey in North London was chosen as the setting for this study, primarily because it was the location of my clinical practice as Consultant Admiral Nurse working with families affected by dementia. My position within the Trust and clinicians' knowledge of me and my research positively facilitated the process of recruitment and conducting the exploratory study. Geographically, the borough of Haringey covers an area of more than 11 square miles in North London, bordering clockwise from the North: Enfield, Waltham Forest, Hackney, Islington, Camden and Barnet (www.haringey.gov.uk).

Haringey is an economically and socially polarised borough and ranks as the fifth most deprived borough in London (www.haringey.gov.uk). It spreads from the affluent suburbs of Highgate, Muswell Hill and Crouch End in the West, to the much poorer areas of Tottenham and Lower Edmonton in the East. According to Office for National Statistics (ONS) estimates, the total population for mid-2013 was 258,900, 3.1% of the total London population (www.haringey.gov.uk). It has an almost equal male to female ratio and an age structure similar to other London boroughs, although the east of the borough tends to have more young people and the west more older people.

It has higher levels of social deprivation in the east and is one of the most ethnically and culturally diverse areas in the UK with over half its population (65%) of non-white British ethnic background (www.haringey.gov.uk). The borough is served by a number of acute hospital trusts, a mental health trust and numerous residential and nursing

homes; community services are provided by the London Borough of Haringey Council. There are an estimated 1,579 PWD in the London Borough of Haringey (www.haringey.gov.uk).

3.5.5 Study setting

As the aim of this study was to include a sample of people with a diagnosis of dementia and their family carers, I chose to work with the older people's services in the BEH Mental Health NHS Trust; memory clinic, community mental health teams and Admiral Nurse services. Given my clinical employment within the Trust, I had direct access to all these services and teams.

3.5.6 Recruitment

The participants [carers and PWD] were recruited from the Memory Clinic, the East & West CMHTs and the Admiral Nursing Service in the London Borough of Haringey specialist mental health services for older people of BEH Mental Health NHS Trust. The researcher identified potential participants during attendance at the weekly clinical team meetings and from discussions with clinicians as to their appropriateness for inclusion in the study.

3.5.7 Sampling

Sampling was purposive to ensure that, where possible, participants were demographically representative of the population of the London Borough of Haringey.

The aim was to establish groups of a suitable size to collate sufficient data. Moore (1987) suggests the ideal nominal group (NG) size is between five and nine participants; so minimum sizes were identified within the protocol that complied with this but also allowed for attrition.

Nominal Group 1: Carers

Nominal Group 2: PWD

Nominal Group 3: Dyads (each dyad: a person with dementia and their carer)

3.5.8 Inclusion criteria

- All PWD had to have received a formal diagnosis from the clinical team, as defined by ICD-10 (WHO, 1992).
- MMSE (Folstein et al., 1975) of ≥ 20 ; this threshold was determined by the findings of the review I undertook as part of the preparation for this phase (see chapter two). Three studies investigated the use of the MMSE in an attempt to predict a 'cut off range' that may indicate a point at where a person with dementia may no longer have decision making capacity (Fazel et al., 1999; Gregory et al., 2007; Hirschman et al., 2004). Setting the threshold at 20 or above was guided by this earlier research (Section 2.4.1).
- All participants were assessed as having mental capacity to give consent to participate in the study in accordance with the MCA.
- By virtue of being referred to mental health services for older people, participants with dementia were likely to be over the age of 65 years, though people with young onset dementia were also eligible.

- Carers were defined as family members or friends who were in regular¹⁰ contact with the person with early dementia and were considered next of kin or 'key decision makers' for the person with dementia.
- In the dyad nominal group each person with dementia was to be accompanied by their main carer.

3.5.9 Exclusion criteria

- Carers and PWD who did not have full mental capacity to give consent to participate were excluded from this research.
- Patients and carers who were unable to communicate in English to a degree whereby they would be unable to participate in the nominal groups were excluded from the study. Whilst it is acknowledged that that the ideal would be to use the first language of all potential participants unfortunately the study was not funded to provide interpreters.

3.5.10 Identification and recruitment of participants

3.5.10.1 Identification

Each potential participant was identified through the researcher meeting with the clinical teams during weekly allocation or multi disciplinary meetings. Clinicians would identify potential participants and from there the researcher would make personal telephone contact to discuss the study. Assessment of capacity to give consent and MMSE score was made by both the referring clinician at the point of identification and

¹⁰ 'Regular' was defined as a family member, friend, etc., who was nominated as the closet individual and had frequent contact by the person with dementia.

then later by the researcher at the point of recruitment to affirm the person with dementia met the inclusion criteria.

3.5.10.2 Recruitment

Each potential participant was contacted by the researcher by telephone and a verbal explanation of the study; this was followed up by posting an information sheet (Appendix 6). After a minimum seven day period, allowing time to read the information and discuss with others, if wished, a second telephone contact was made to seek consent for inclusion in the study. Full opportunity was offered at each point for participants to ask questions or seek clarification about the study. The researcher carefully explained any points in the information sheet that had not been understood. A letter confirming the date and venue of the nominal group was then sent to each participant that agreed to participate.

During discussions with participants in the recruitment process, the researcher indicated that the outcome of their participation in the NG may not accrue direct benefit to them but would add to the body of knowledge about dementia. Findings may benefit PWD in the future and give the participants an opportunity to improve the provision of services in their area and beyond. This was made clear to all participants before they decided whether or not to take part and was also outlined in the information sheet.

3.5.10.3 Obtaining informed consent

All participants were asked to initial and sign a consent form (Appendix 7) that was then countersigned by the researcher. Copies were given to each participant, one held in the care records of the person with dementia and one saved in the study

documentation file. The principles of the Mental Capacity Act were adhered to (Figure 3.1) in ensuring that both PWD and carers had the capacity to give informed consent and participate in this study and to take part in the NG.

The person with dementia's general practitioner was informed of their inclusion in the study, as is standard practice in clinical research (Appendix 8). NGs were held in the local memory clinic meeting room. Transport was offered to all potential participants.

Figure 3.1 MCA (p 45) – 4 point framework for assessing capacity

A person with capacity to make a decision should be able to:

1. Understand [relevant] information about the decision to be made
2. Retain this information in their mind
3. Use or weigh that information as part of the decision-making process
4. Communicate their decision

3.5.10.4 Demographic Data

Baseline data were recorded on the demographics of the PWD and carers, including age, gender, ethnicity, previous education and employment and living situation. In addition the carer was asked what their relationship was with the person with dementia.

3.6 Conducting the Nominal Groups

The data were collected from three NGs held on different days between October 2009 and January 2010.

- | | |
|--------------------------------------|---------------|
| 1. Carers of PWD | October 2009 |
| 2. PWD | December 2009 |
| 3. Dyads of both PWD and their carer | January 2010 |

All NGs were held in a large quiet meeting room within the memory clinic on a day when clinics were not held. Lunch was provided at the commencement of each session with refreshments available throughout.

Each session was led and facilitated by the researcher (KHD) and supported by an experienced Admiral Nurse from BEH Mental Health Trust Admiral Nursing Service (KE). This enabled sufficient support to any individuals that required help during the NG process and also to offer support away from the group should any one participant become distressed. No participants became distressed during any of the groups, nor to our knowledge afterwards.

At the close of each NG, participants were each given a booklet on ACP (Henry and Seymour, 2012) and the option of contacting the Admiral Nursing service at a later date if they wished to go on and develop an advance care plan.

3.6.1 The Nominal Group Process

A modified NGT using 5 stages was used across all three groups (3.4.7). To ensure consistency a 'nominal group schedule' was developed that guided the researcher to introduce the format for each of the five stages of the NGT process and gave a basic introduction to ACP (Appendix 9). The final and fifth stage invited individual group members to rank their own preferences using a printed template (Figure 3.1) from the

priorities generated. This final stage of the process was modified; ranking was undertaken on an individual basis to allow all participants to determine their own priorities for future wishes and preferences, rather than voting collectively as would normally be done (Delbecq and Van Den Ven, 1971). This later enabled me to develop a collective ranking score from the individual ones.

The researcher felt the NGT method would allow the absolute views of each person with dementia to be recorded (3.4.2) and allow them to derive a sense of achievement at the end of the process (Harvey and Holmes, 2012). Five stages of the NG would take a maximum of 90 minutes, the estimated maximum amount of time PWD would be able to tolerate. However, as the stages were short and interspersed with conversation, it proved readily possible to retain individuals' attention. The sessions involved social elements of introductions and refreshments before and after the NG to enable people to relax into the process, and similarly, at the end (3.4.3).

The five stage NG schedule and process was successfully piloted with a group of Admiral Nurses (n = 8) during a professional practice development session. The pilot paid particular attention to the clarity of the process.

The nominal groups were digitally recorded so that those stages that involved discussion were captured for later transcription verbatim and qualitative content analysis using content analysis (Ritchie and Lewis, 2012), supported by NVIVO 8 qualitative analysis software (QSR International, 2008). A particular focus of this analysis was to examine to what extent the process of identifying wishes and priorities for future care was affected or influenced by the presence of both the carer and the person with dementia.

3.6.2 Opening Introduction

The facilitator or researcher opened each group by thanking participants for taking part and indicated that there were two other similar groups being held on different days. The concept of advance care planning was explained including brief detail of the issues around making known in advance wishes that may apply when a person is less able to express these wishes (Appendix 9).

It was stressed that the process was about improving our understanding of what PWD see as important factors to influence the care they would want in the future in later stages of the illness when they may not be able to say so. Carers were not specifically asked to consider what their own wishes and preferences would be in a situation where they too had dementia but just to consider generally.

A brief explanation of the purpose of the Mental Capacity Act was offered and a person's statutory right to state what forms of care they would or would not like to receive. To allow participants to understand what issues they might want to consider, one example was presented to each group:

*It may be a priority to you that you continue to go to church each Sunday –
that your spiritual well being is of a high priority*

They were then invited to consider what their wishes and priorities for future care might be in the nominal group.

3.6.3 Stage 1: Generation of ideas

This stage lasted approximately 10 minutes. The objective of the first stage was to facilitate contributions from all group members. The participants were asked to consider what their preferences for care would be if their health deteriorated and death approached. They were invited to write down a word or short statement for each onto a [sticky back] 'post it' note. It was stressed that all ideas were valued and would be documented and used in the final evaluation. They were told that there was no limit to the number of ideas they could generate. This stage of the NG process usually aims for silent generation of ideas (Delbecq and Van De Ven, 1971; Van De Ven, 1971). However, remaining silent may be rather threatening for PWD. The researcher and Admiral Nurse offered reminders of the purpose of the group and provided assistance or offered to help in writing thoughts down.

Every care was taken to reduce the potential for bias through researcher influence. The Admiral Nurse facilitator was briefed in the NGT method, and taking field notes. She was instructed not to offer suggestions, influence or question the participants' choices and responses.

The protocol allowed approximately 10 minutes for the generation of ideas or stopped when it became apparent that each individual had exhausted their generation of ideas, whichever was the shorter. All written thoughts were then collected in readiness for stage two.

3.6.4 Stage 2: Discussion

This stage lasted approximately 15 minutes and is often referred to as a 'round robin' way of recording ideas (Delbecq & Van De Ven, 1971) and was characterised by a

structured and time-limited discussion of all ideas each participant had generated. The purpose of the discussion was to clarify ideas, explore the underlying rationale and to add any further items that emerged through discussion, ensuring that each participant felt that their contributions were valued. As each idea was discussed it was placed on a central board in full view of all participants.

3.6.5 Stage 3: Further generation of ideas

This stage lasted approximately 10 minutes. The participants were given a further period of silent generation and asked to consider any additional ideas arising after hearing those of others. These were also collated and placed on the central board.

3.6.6 Stage 4: Discussion and generations of themes

This stage lasted approximately 10 minutes. All contributions were again discussed for the purpose of generating common themes. Finally, each group formulated statements to reflect the themes. This group process ensured face validity of themes.

3.6.7 Stage 5: Individual ranking

Rather than voting collectively, ranking was undertaken individually to allow all members to determine their own priorities. This enabled PWD to express their preferred choices independently of other group members. The participants ranked their five most important items from the themes displayed on the display boards; one being the most important and five being the least important (Figure 3.2).

Figure 3.2 Ranking sheet.

Participant No:	
1 (Most Important)	
2	
3	
4	
5 (Least Important)	

3.7 Data Analysis

Simple descriptive statistics were used for quantitative data.

Two approaches were taken to ensure face and content validity of the emerging themes:

1. Collation of themes and scoring of the individual ranked items
2. Qualitative content analysis of discussion transcripts

3.7.1 Scoring of individuals' ranking of themes

The researcher assigned a score to each of the five highest individually ranked items to identify summative ranked priorities for each group. A scoring system was constructed for the purpose of identifying overall priorities ranked by individuals (highest ranking = 10; lowest ranking item = 2). A group score for each item raised in each group was

derived by summing the individual scores for each, which then provided a ranking of items from each of the three groups. Finally, all group scores were collated to give an overall priority of items from all three groups.

3.7.2 Qualitative content analysis

Data collection and analysis were simultaneous beginning with the first nominal group and then continued with each group. Qualitative content analysis is the process of identifying, coding and categorising patterns as they emerge from the data (Ritchie and Lewis, 2012; Coffey and Atkinson, 1996).

The data were divided and organised, within NVIVO8, supported by manual coding and theming independently and then collectively by the researcher (KHD) and supervisor (ELS) to ensure reliability and validity. The data tree and themes were then agreed upon by KHD and ELS).

3.8 Results

3.8.1 Participant characteristics

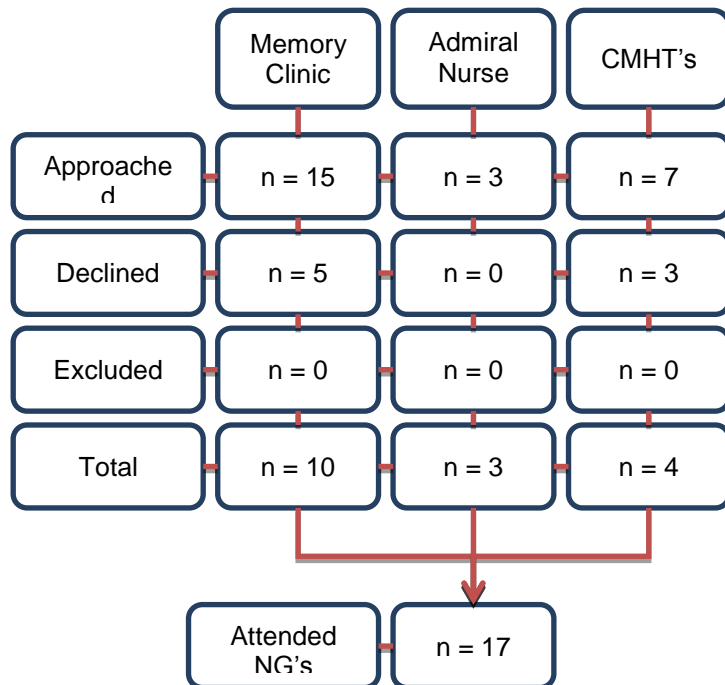
Twenty-five people agreed to participate, of whom 17 attended: nine PWD and eight carers (Figure 3.2) (Table 3.1). The average age of participants with dementia was 83.3 years (range 75 to 91 years). Their average MMSE score was 24.2 out of 30 (range 22-27). The average of age of carers was 69.2 years (range 52 to 84 years). Reasons given for non-attendance were various e.g. stress, work pressures or no reason offered (Table 3.2). All participants recruited to NG2 attended, this was thought

to be due to the provision of transport. Transport was declined by groups one and three as carers managed this for themselves and for the dyad group.

3.8.2 Nominal Group One (NG1): Carers of a person with dementia

Ten carers of a person with a diagnosis of dementia were invited into NG1. There was a 50% attrition rate with five carers failing to attend the nominal group; reasons given were work pressures, carer stress or no reason given.

Figure 3.3 Recruitment to nominal groups



Among the five who attended, the mean age was 66.8 years (range 52 to 84 years). Three members of the group were female and four were of White British ethnicity. All group members were educated to higher level (see table 3.1). Three were spouses and lived with the person with dementia. Two were adult children, one living with her mother and one whose parent was in a care home.

3.8.3 Nominal Group Two (NG2): PWD

Six people with a diagnosis of dementia meeting the inclusion criteria were recruited to NG2. Diagnoses were recorded by ICD-10 categories; three diagnoses of dementia: Alzheimer's of late onset (F00.1), two with an atypical or mixed type Alzheimer's

(F00.2) and one with Alzheimer's of an unspecified type (F00.9) (Table 3.1). All participants were diagnosed between March 2008 and September 2009, i.e. they were between 3 months and 21 months post-diagnosis at the time the NG was held. The participants' mean age was 83.8 years (range 77-90 years). Their mean MMSE was 24.1/30 (range 22-27). Four of the group were female and three were of White British ethnicity. Half the group had received a college education, two had left school with no qualifications and one had a degree. Four lived alone in their own homes either in the community or in sheltered housing. One lived with their spouse and one lived with an adult child.

3.8.4 Nominal Group Three (NG3): Mixed, carers and PWD

I aimed to recruit a minimum of four dyads (carer and the person with dementia) into NG3 who all consented to take part but only three dyads attended. Invitations were extended to five dyads to allow for attrition. In this group the carer and the person they care for with dementia attended the group together.

Table 3.1 Characteristics of participants (n = 17)

	People with dementia (PWD)	Carers
Age (Overall)	83.3 years (n = 9)	69.2 years (n = 8)
Carer NG 1		
Dementia NG 2	83.8 years (n = 6)	66.8 years (n = 5)
Dyad NG 3	82.3 years (n = 3)	73.3 years (n = 3)
MMSE (Overall)	24.2	
Dementia NG 2	24.1	-
Dyad NG 3	24.5	-
Diagnosis		
F00.1 (Alzheimer's late onset)	4	-
F00.2 (atypical or mixed type Alzheimer's)	4	-
F00.9 (Alzheimer's of unspecified type)	1	-
Gender		
Male	3	3
Female	6	5
Ethnicity		
White British	5	5
White European	1	2
White American	1	1
Black Caribbean	1	-
Asian British	1	-
Previous education		
Degree or above	2	6
College	3	-
Left school with no qualifications	4	2
Living situation of PWD		
Alone	4	-
Spouse	3	-
Child	1	-
Sibling	1	-
Relationship to PWD		
Spouse	-	5
Son/Daughter	-	2
Sibling		1

Notes: NG = PWD = Person with Dementia. Nominal Group. MMSE = Mini Mental State Examination.

Table 3.2 Non-attendance for groups

Nominal Group	DNA	Reasons given
1. Carers	5	Carer stress (n=3), work pressures (n=1), no reason given (n=1).
4. People with dementia	-	-
5. Dyads	2 (n = 4)	Carer stress (n=3), no reason given (n=1).

Diagnoses were recorded by categories identified within 1CD-10 (WHO 1992) as for NG2; one diagnosis of dementia Alzheimer's of late onset (F00.1) and two with an atypical or mixed type Alzheimer's (F00.2) (Table 3.1). All participants were diagnosed between March 2008 and September 2009.

In the event, three dyads attended NG3. The average age of participants with dementia was 82.3 years (range 75-91 years), the average age of carers was 73.3 years (range 70-77 years). The relationship between were two spousal and one sibling.

3.9 Process

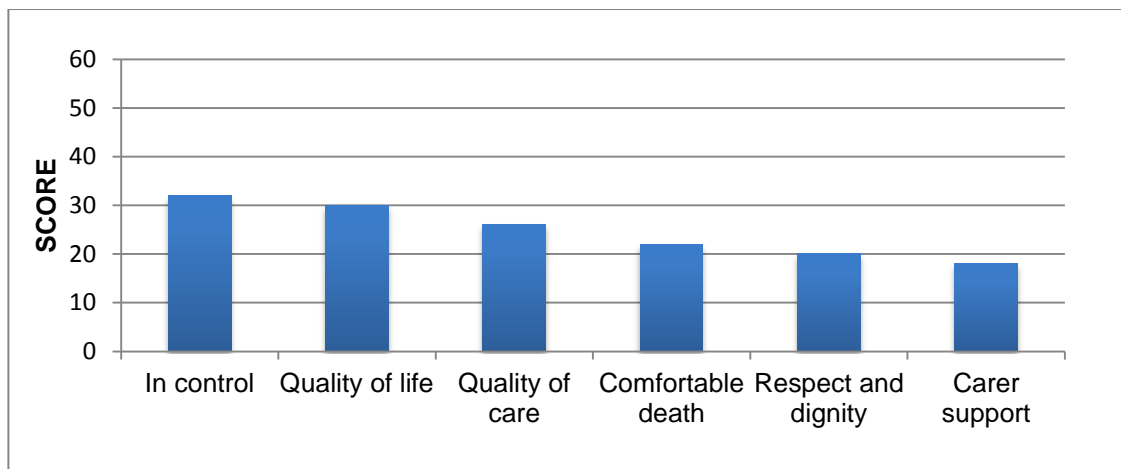
I found that PWD required reminders and support from the groups' co-facilitator (Admiral Nurse, KE) at each stage of the process. People with dementia in NG2 required most help. In NG3, family carers tended to intervene if the person with dementia required support in all but the ranking stage because instructions for this part of the process was for individuals' to do this without conferring (section 3.5.7).

3.9.1 Ranking of items

NG1 - Carers of PWD

The NG process generated six priorities that participants, currently caring for a person with dementia, identified as factors they considered important when asked to think about their preferences regarding their own end of life care. Their ranking of items in order of priority (Figure 3.4) was as follows: to be in control, to have a good quality of life, to have good quality care, to have a comfortable death, to be treated with respect and to have carer support.

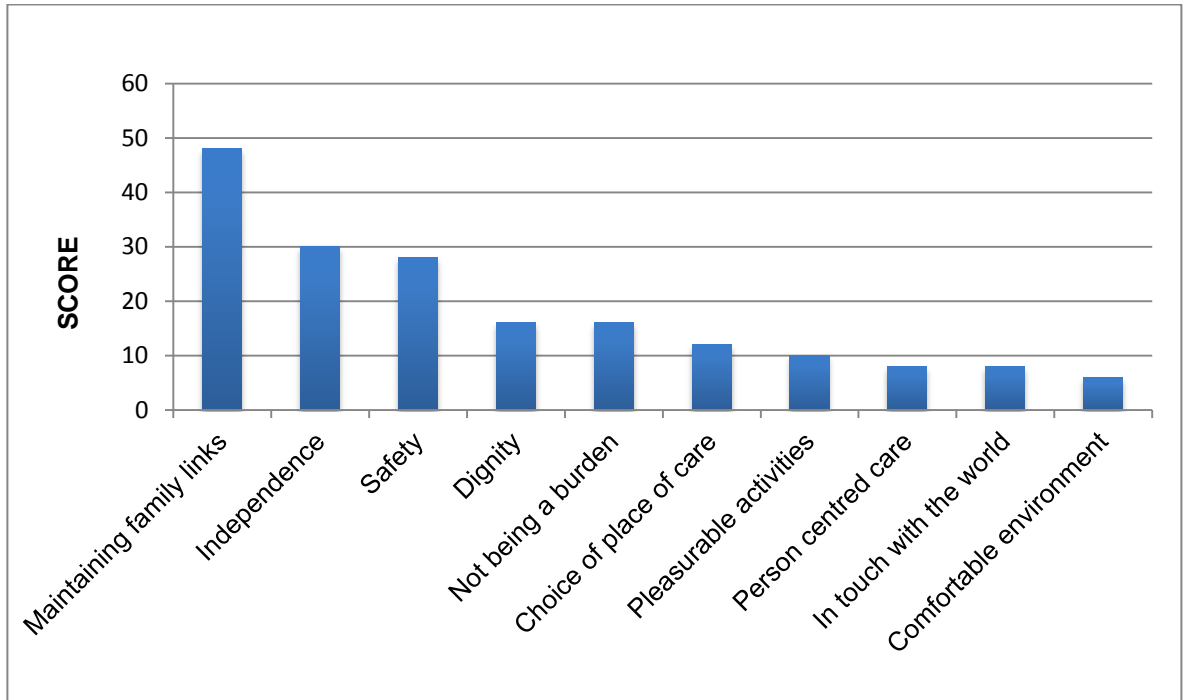
Figure 3.4 Ranking of items: NG1 (carers of PWD)



NG2 - PWD

The PWD in NG2 came up with a longer list of 11 items, which they ranked in order of priority as follows: to maintain family links, to maintain independence, to feel safe, not to be a burden, to be treated with respect and dignity, to have a choice in their place of care, pleasurable activities [to take part in], to have person-centred care, to be in touch with the world and to have a comfortable environment (Figure 3.5).

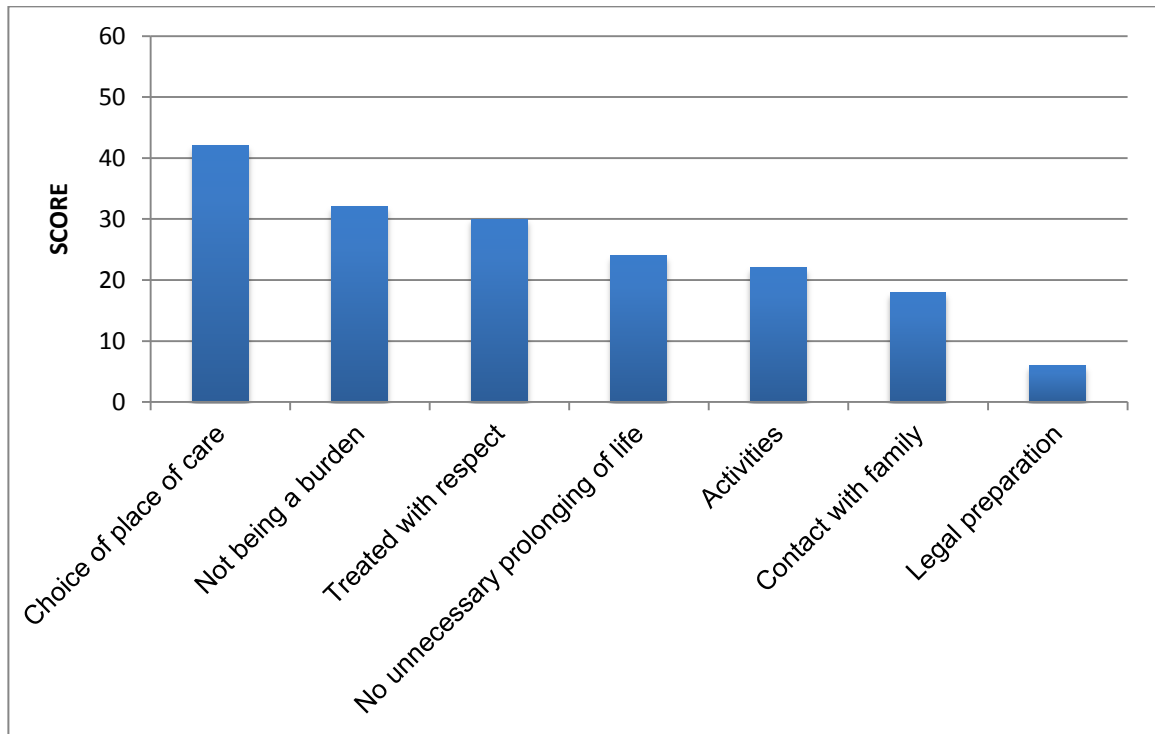
Figure 3.5 Ranking of items: NG2 (PWD)



NG3 – Dyads (Carers and PWD)

Some but not all of the items proposed by NG3, the group with carers and PWD together, had been suggested by the two separate groups. NG3's seven items were ranked in order of priority as follows: choice of place of care, not to be a burden, to be treated with respect and dignity, no unnecessary prolonging of life, activities [to take part in], to maintain contact with family and to make legal preparation (Figure 3.6).

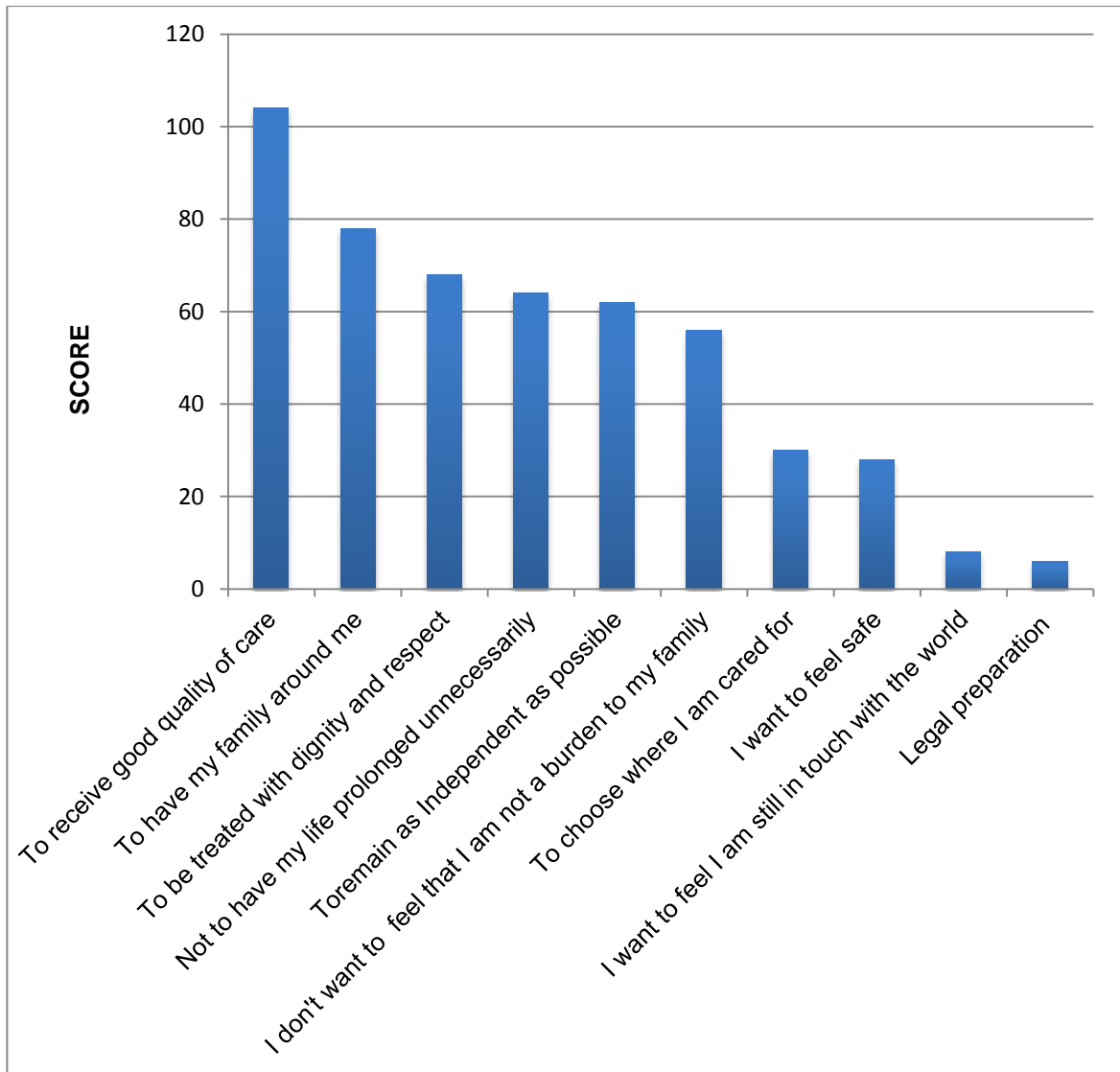
Figure 3.6: Ranking of items: NG Three (PWD and their carer)



Combined priorities of NG1, NG2 and NG3

Overall priorities for NG1, NG2 and NG3 were calculated from scores of individually prioritised items (Figure 3.7). The three highest ranked items of the combined scores from all three NGs were the wish to receive good quality care, to have one's family close by and to be treated with dignity and respect at the end of life.

Figure 3.7 Ranking of items: Combined score of all NGs



3.10 Emergent Themes

The themes arising from individual ranking and content analysis of discussions were essentially similar, which supported content validity. The themes generated will be discussed:

- Good quality care
- Independence and control
- Perceptions of carer burden

3.10.1 Good quality care

The most prominent theme for all participants was the wish to receive good quality care at the end of life. As the focus of all groups was for participants to consider their own wishes and preferences for end of life care, carers wished for continued control over their own care, if and when they might need support in the future. In describing good quality care, PWD talked of their lives very much in the ‘here and now’, the elements of this being activities they currently enjoyed and valued. They seemed unable to consider their *future self* or that at some point valued activities would alter or perhaps cease altogether:

...well, I go back and forth [to Ireland]...I will continue to do that...

Person with dementia 05 (NG2)

Carers talked extensively about their perceptions of poor quality care, based upon media coverage at the time of the NG and reflections of personal experiences of caring for a person with dementia, and framed this as care that they *would not* want for themselves. Several spoke of care that was ‘desirable’:

...non institutionalised care...carer support to stay at home...it should be with one person coming in...things [personal care preferences] that appear not to be important and unrelated to health but actually take a much higher place.

Carer 04 (NG1)

Carers made many references to what they perceived as undesirable or poor quality care, both in a care home setting and that delivered in their own homes. A trail of different people providing intimate day by day care was felt to be care of low quality:

[care at home]...people having someone different coming in to wash them every day or whatever is horrendous...

[care home]...also...the institutionalised thing, it fills me with dread, this idea of people sitting around a room in green plastic chairs

Carer 01 (NG1)

People with dementia also made reference to quality care:

...to look after me with care...don't treat me like a vegetable...like a mad person.

Person with dementia 01 (NG 3)

All NGs mentioned dignity and respect as being synonymous with good quality care and future wishes, but participants found these difficult concepts to define when pressed. The carers felt that poor care arose from an underlying lack of respect for PWD, which therefore robbed them of their dignity.

3.10.2 Independence and control

The participants with dementia saw 'independence' as a broad and intangible aspect of their future, making assumptions that they would retain independence. The carers (NG1) considered a future time when they themselves might lack decisional capacity. There was general fear and uncertainty with a lack of trust in medical decision making.

...being sure that treatment is in my best interests...It means that you have got to trust in people who make the decisions...

Care 01 (NG1)

In the dyad group (NG3), carers tended to speak on behalf of the person with dementia, thus influencing the collective view. The PWD found it difficult to consider preferences and wishes about their end of life, with little sense of the potential value of ACP or how expressing preferences and wishes *now* could influence care later. However, one person with dementia considered where they may die and had a clear preference to die at home:

...that's a nice place to die...home...

Person with dementia 02 (NG3)

The carers felt it was difficult to plan ahead and anticipate what may or may not happen:

...you don't know what changes will happen, when it will happen...that's why [ACP] is very difficult to define.

Carer 05 (NG1)

The carers felt that medical decision-making and the use of end of life care pathways could invalidate their ACPs:

...you are put on the short count to death now [End of life Care Pathways]...I think a lot of elderly people are put on that path because it happens to be

convenient...just because they are old basically, the plug is pulled...that decision can sometimes be made too early.

Carer 03 (NG1)

The carers expressed scepticism about whether ACP would allow them to retain control. They thought that ACP may be a process with no firm outcomes open to (mis) interpretation by professionals:

...consolidates my slight fear about this sort of advanced care planning that it takes away [control] from individuals even though it's prepared by an individual; you have to tick certain boxes.

Carer 04 (NG1)

Several carers (NG1 and NG3) felt the only way to ensure that control was retained was to take matters into their own hands through assisted dying and euthanasia. Once the topic had been raised, a growing confidence developed in NG one and many felt similarly, to the extent that one member used the term 'suicide'. While acknowledging that euthanasia is not legal in the UK, NG1 reached a consensus that you cannot discuss ACP without considering this.

...it is interesting for people to know in the back of their mind that even if it's a subject we cannot go [not legal in the UK] that actually it looks as though quite a few of us were feeling that.

Carer 02 (NG1)

It was highlighted that if end of life care was better, individuals would not need to contemplate euthanasia:

...I feel...that if, you know, ...the end of life...sort of thing came up as...sort of satisfying more people...possibly going down the suicide route would evaporate you know.

Carer 03 (NG1)

By contrast, some PWD in NG3 felt that, irrespective of the quality of care, they would not want to continue living:

...change, feeding, some people [...]...is not right...if I am unwell and not enjoying my life and a vegetable [...] I would like to...I would be better off dead.

Person with dementia 03 (NG3)

...when I...am that bad...I would rather die...

Person with dementia 01 (NG3)

Summarising their views on ACP, NG1 felt that carers' needs should also be taken into account:

...it's having support to [do] whatever you want to do at the end, in the most comfortable way, not only for you but also for your carers.

Carer 01 (NG1)

3.10.3 Perceptions of burden and caring

Having continued contact with family, friends and loved ones in the future was highly valued by all groups. The PWD and carers discussed the nature of caring and not

wanting to become a burden to their families. However, whereas the burden discussed by carers was subjective and based upon their current experiences and from the recent negative media exposure of care homes (BBC 2009), PWD had no perception of the sense of burden they generated on their carers and talked about burden as something that *may* occur in the future with little perception of the current situation:

[Burden]...only if I were totally dependent upon them...

Person with dementia 01 (NG2)

...well that's what you get [to be a burden]...not there now...

Person with dementia 02 (NG2)

The PWD spoke positively about their families and their relationships with them, seeing the value of continued family contact. This was felt across all types of relationship: spousal, sibling, children etc. However, the carers in NG3 often spoke over the person with dementia, pointing out that they did not want *their* children to find themselves in a similar position:

I don't want to leave my son with things like that [making decisions and providing intimate care].

Carer 01 (NG3)

Spousal carers appeared more accepting of their role, whereas siblings or adult children talked of the overwhelming difficulties of caring. One carer experienced such stress that should she also be affected by dementia, she had told her children that she wanted to go into a care home. She did not want her relationship with her children to be damaged by burden or responsibility:

...being a carer is difficult...it leaves some nasty memories...

Carer 02 (NG3)

The carers challenged 'the system' arguing that if health and social care were effective in supporting PWD and their carers, 'burden' would not be an issue.

3.11 Discussion

The summary of the main findings from phase one were that:

- PWD find it challenging to consider their preferences and wishes for end of life care.
- Carers' own preferences are influenced by current experiences of caring.
- In dyads, the carers' views tended to override those of PWD.

Both PWD and carers had difficulty with some concepts, for example, dignity and respect, terms often used liberally by professionals in health and social care settings and ACP discussions. PWD tended to think in a 'concrete way' and struggled to think about their future, as seen in previous research, and often framed their views solely in their present context (de Boer et al., 2012). Thus, albeit that recent research demonstrates some success in introducing the utility of ACP soon after diagnosis (Poppe et al., 2013), in practice, even people with early dementia may have difficulty in participating fully in ACP as to do so requires them to imagine their 'future self'. However, discussing death and dying generally requires us to confront deeply held social taboos whatever the disease process is (Mason et al. 2011). Fazel et al. (1999)

and Gregory et al. (2007) reported that MMSE scores above a cut-off point of at least 18-20 were required to make an ACP. However, most PWD participating in the NGs experienced difficulty with the concept of ACP despite having been diagnosed with dementia with a 'mild' severity rating, MMSE scores of at least 20 [mean 24.2; range 20-29] and over half having had further or higher education.

Consistent with other research (Reamy et al., 2011), carers' own preferences were articulated within the context of their caring experience, which was often negative and influenced by adverse media coverage of dementia and by the nature and quality of their relationship with the person with dementia. Carers reflected on what their own future might hold based upon their perception of what they felt it was like for their relative to *have* dementia: in a care system currently under much criticism, with inadequate carer support and a future that holds a degree of uncertainty when dementia presents itself (Robinson et al., 2013).

Whilst carers acknowledged some situations that may require specific decisions (e.g., care home admission, tube feeding, resuscitation), they felt such decisions would be made by healthcare professionals irrespective of ACP and were beyond their own influence. During the period of conducting the groups, there were various contextual aspects of end of life care that were receiving negative media attention. The Liverpool Care Pathway (LCP) was receiving considerable media coverage, under public scrutiny and criticism because of the potential for its mismanagement (Devlin 2009; Millard, 2009). Carers of NG1, in particular, expressed concerns that this was a 'short count to death' and expressed mistrust of medical decision making at end of life, doubting their best interests would be of prime concern. The LCP has since been the subject of an independent review (DH, 2013a), chaired by Baroness Julia Neuberger, with the

recommendation that it be phased out within a six to 12 month period. The UK government readily accepted this recommendation. Whilst this action has been challenged by many within the end of life care field (for example; Sykes, 2013; Currow and Abernathy, 2014), public unease had been mounting for some time.

Thus, carers in this study felt that an advance care plan might not be a document that was sufficiently robust enough to enable their own preferences for end of life care to be enacted when their decisional capacity was lost. Conversely, if *no* advance care plan was made they felt that they may equally be subjected to poor end of life care through being placed on the LCP which they perceived negatively. Carers therefore desired absolute autonomy for deciding their own care if debilitating illness ensued, expressing a possible wish for assisted dying or euthanasia.

Despite evidence that ACP can contribute to the quality of remaining years in life-limiting conditions (Molloy et al 2000a), guide family members (Seymour et al., 2004), and take the 'burden' out of making end of life decisions (Horne et al., 2007), it may still have limited potential for addressing future issues, either because of a desire to live in the present or because the prognosis is unclear (Barnes et al., 2011; Low et al., 2011). This work suggests that impaired cognitive function may bring additional problems, as PWD find it difficult to conceive of their future self and possible burdens that their illness places on those around them. This situation is further complicated by the frequent co-occurrence of physical illness with dementia, thus making it even harder for the person to imagine what medical care decisions need to be made.

Making treatment decisions for older people is difficult when they lose the capacity to tell us what they want: a person needs to feel trust in a family carer's ability to make

such decisions (Piers et al., 2011) and need to rely on their family members to indicate to others what their wishes and preferences might have been (Aw et al., 2012). Often family carers may be petitioned as to the wishes and preferences of a person with dementia at a time of crisis or care transition, for example admission to a care home or acute hospital. Seeking ACP discussions at these highly emotional points can be less than suitable and carers can be reluctant to engage (Sampson et al., 2011). Some studies have explored levels of agreement between people with long-term illness and their family carers and indicate varying levels of concordance (Ahluwalia et al., 2011). In a qualitative study of dyads involving heart failure, Retrum et al. (2012) found that lack of agreement could impair the ACP process (Section 1.8.6). This may well occur in dementia too.

Carer burden and distress were consistent elements that were threaded through the NG data with a sense of foreboding when attempting to look into the future for the person with dementia and also for carers themselves. In their study of ACP in the acute hospital setting, Sampson et al. (2011) found that carers viewed planning ahead as an impossibility and took a 'one day at a time' approach to decision making.

When a person with dementia has lost the ability to make their own decisions in relation to end of life care and treatment it is often the close family members who are first to be consulted: 'What would he/she have wanted in this situation'? To ensure that we can be as certain as possible in the midst of uncertainty about (Robinson et al., 2012) there are various aspects of proxy decision making that require further exploration. In Chapter four of my thesis I explore carer factors that may be influential in their decision making on behalf of the person with dementia, and a carers ability to agree or predict the treatment preferences of the person with dementia.

3.12 Strengths and limitations of phase one

The use of NGs allowed each participant equal opportunity to contribute, supporting and valuing individual views. One group solely consisted of PWD as I was keen to hear their opinions away from their carers’.

The NG process was piloted for its clarity with a group of Admiral Nurses; however, it may have been more appropriate to have done so with a small group of PWD and carers to also seek validity of both process and content.

NG3 included PWD and their carers together so I could examine whether their interaction affected the ability of PWD to express a view. However, as this was only one group, the ability to explore this was limited.

Although the sample size was small and restricted to one locality, it represented a range of ethnicities, types of carers, living situations and levels of education (Table 3.1). Although not necessarily generalisable, data were obtained directly from PWD and their carers’.

Although discussions did not cause overt distress, interaction in a group setting was limited and a ‘one-to-one’ approach might be more supportive. Carers tended to prioritise their own opinions, so we should be cautious if families speak for their older relatives, for example, if English is not their first language. However, without funding for interpreters, we were unable to explore this further.

When reflecting on the NG process, to enable participant’s to understand what issues they might want to consider, I offered the example that a priority might be *to continue to*

go to church each Sunday. Whilst no participant's raised concerns, this example would not have been appropriate to all participants" given the potential for a wide range of ethnicity, cultures and religions. In conducting such a study again an alternative example would be employed.

The conclusions to the nominal groups (as for the conclusions to Chapter 1 and 2) will be presented in Chapter 7 which draws together all the conclusions of all elements of the thesis.

**CHAPTER 4: PHASE TWO – AGREEMENT: A CROSS SECTIONAL
INTERVIEW STUDY**

4.1 Aims

My aim was to explore carers' understanding of the wishes and preferences of the person with dementia for whom they care, their ability to predict those preferences and factors which influence this. The findings may enable health and social care professionals to better support advance care planning for families affected by dementia.

4.1.1 Objectives

- 1) To examine agreement between PWD and their family carers concerning the use of life sustaining medical treatments at the end of life^{11,12}
- 2) To explore which clinical and demographic factors influence agreement in dyads. These include:
 - a. for the person with dementia: cognition, quality of the care-giving relationship with their carer
 - b. for their carer: quality of the care-giving relationship with the person with dementia; distress; perceived carer burden.

¹¹ There is no exact definition of end of life. However, the evidence supports the following components: (1) the presence of a chronic disease(s) or symptoms or functional impairments that persist but may also fluctuate; and (2) the symptoms or impairments resulting from the underlying irreversible disease require formal (paid, professional) or informal (unpaid) care and can lead to death. NIH Consensus development programme: <http://consensus.nih.gov/2004/2004EndOfLifeCareSOS024html.htm>

¹² End of life care is an important part of palliative care, and usually refers to the care of a person during the last part of their life, from the point at which it has become clear that the person is in a progressive state of decline. <http://www.avert.org/palliative-care.htm>

- 3) To pilot a modified version of the Life Support Preferences Questionnaire (LSPQ).

4.2 Research questions

The research questions I wished to explore were:

1. PWD and their family carers agree on preferences regarding life sustaining medical treatments at the end of life care.
2. Good care-giving relationships and lower levels of perceived carer burden and distress improve agreement and a carers ability to predict preferences regarding life sustaining medical treatments at the end of life.

4.3 Study Design

This was a cross sectional interview study involving PWD and their carers attending memory clinics within mental health services for older people, known to community mental health teams and dementia research registers in four different sites.

4.4 Methods

4.4.1 Study setting

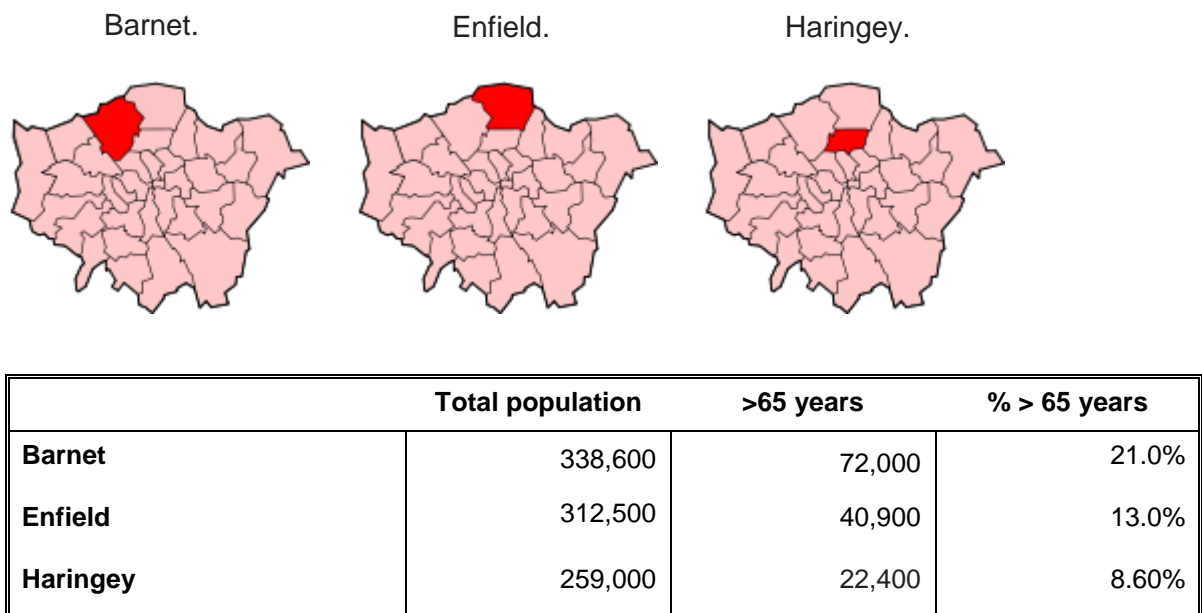
The study setting was mental health services for older people. Participants were recruited from various services including: memory clinics, community mental health teams and research registers.

4.4.2 Study Location One - Barnet Enfield and Haringey Mental Health NHS Trust

The Boroughs of Barnet, Enfield and Haringey in North London were chosen as the primary location for this study as they were served by a single mental health NHS trust. The area was accessible to me as I was employed as Consultant Admiral Nurse in Haringey at the outset of this doctorate.

Geographically, the boroughs of Barnet, Enfield and Haringey (Fig 4.1) cover an area of more than 77 square miles in North London (www.barnet.gov.uk www.haringey.gov.uk; www.enfield.gov.uk).

Figure 4.1 London Boroughs of Barnet, Enfield and Haringey geographic location and older population



4.4.3 Study Location Two - Cambridgeshire and Peterborough Foundation Trust

Cambridgeshire and Peterborough Foundation Trust (CPFT) was the second site approached. R&D approval was sought for Cambridge and Cambridgeshire, not Peterborough. Cambridgeshire covers an area of approximately 1,309 square miles, about 50 miles north of London (Fig 4.2). Cambridge City is distinctive due to its large student population, which has the effect of reducing the proportions of the total district population made up by other age groups (www.cambridge.gov.uk).

Figure 4.2 Cambridgeshire and Peterborough geographic location and older population

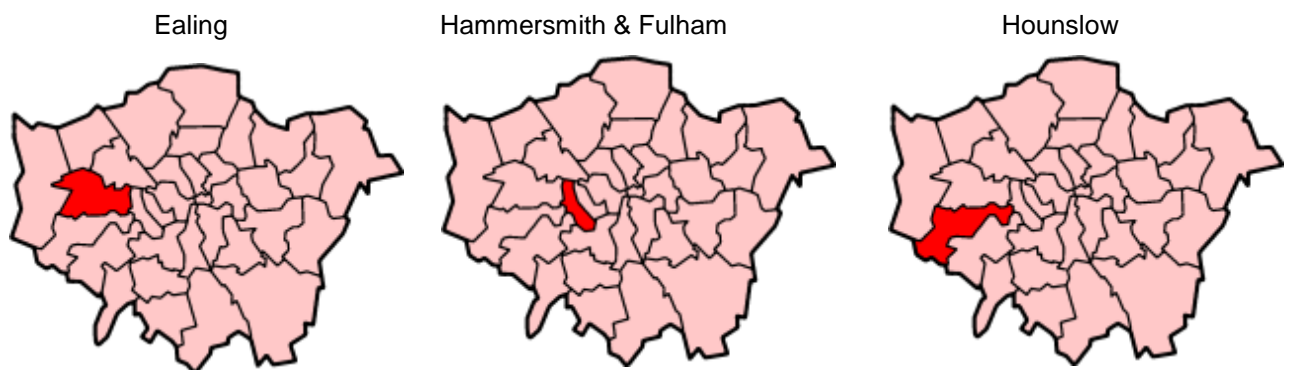


	Total population	>65 years	% > 65 years
Cambridgeshire	620,100	100,229	16.0%
Cambridge City	124,000	14,600	11.7%

4.4.4 Study Location Three - West London Mental Health NHS Trust

West London Mental Health NHS Trust (WLMHT) is one of the largest and most diverse mental health services in the UK, serving a population of around 700,000 residents in the London boroughs of Ealing, Hammersmith & Fulham and Hounslow (www.ealing.gov.uk www.lbhf.gov.uk www.hounslow.gov.uk).

Figure 4.3 London Boroughs of Ealing, Hammersmith & Fulham and Hounslow geographical location and older population



	Total population	>65 years	% > 65 years
Ealing	338,449	36 227	10.70%
Hammersmith & Fulham	166,200	16,800	10.10%
Hounslow	254,900	24,993	9.80%

4.4.5 Study Location Four – Leicestershire Partnership NHS Trust (LPT)

Leicestershire Partnership NHS Trust provides integrated mental health, learning disability and community health services to a population of one million people across Leicester, Leicestershire and Rutland. Leicestershire and Rutland are both counties in central England (www.rutland.gov.uk/) (www.lsr-online.org).

Fig 4.4 Leicestershire and Rutland geographic location and older population older population



	Total population	>65 years	% > 65 years
Leicestershire	650,500	115,500	17.7%
Rutland	37,369	8,200	21.9%

4.4.6 Study Sample

Participants were identified either by older people's mental health clinicians or research assistants from DeNDRoN (Dementias & Neurodegenerative Diseases Research Network¹³) dementia research registers (BEH and WLMHT), community mental health teams (CPFT) and memory clinics (BEH, LPT).

4.4.7 Study population

The study population consisted of dyads, each dyad comprising a person with a diagnosis of dementia and their family carer or friend.

4.5 Inclusion & exclusion criteria

Exclusion criteria were kept to a minimum in order to maximise the potential for recruitment and to preserve the generalisability of the findings. Minimising refusals was essential, in order to reduce participation bias. This is known to be potentially problematic, especially in cross sectional studies where a minimum response rate of 70% would be considered to be acceptable, providing the demographic profiles of participants are similar to those of the non-participants (Boyle, 1998). Therefore, the reason for decline and demographic data on non-participants, where possible, was sought.

4.5.1 Inclusion Criteria - PWD

- A clinical diagnosis of dementia of any type as categorised in ICD-

¹³ <http://www.crn.nihr.ac.uk/dementia/>

10 (WHO 1992).

- MMSE \geq 20.
- Have mental capacity to consent to the study and to participate in the interview.

4.5.2 Exclusion Criteria - PWD

- MMSE $<$ 20.
- Lack mental capacity to consent to the study or participate in the interview.
- Those PWD where no family carer or friend could be identified or were not agreeable to take part.
- PWD who were unable to communicate in English sufficiently and independently of their carer (as no interpreters were available for the study).

4.5.3 Inclusion Criteria - Carer

- Carers defined as family members or friends who were in regular¹⁴ contact with the person with dementia.
- They must be next of kin or “key decision makers” for the person with dementia.

4.5.4 Exclusion Criteria - Carer

- Carers who lack mental capacity to consent to the study or participate in the interview.

¹⁴ As in Chapter 3, ‘regular’ was defined as a family member, friend, etc., who was nominated as the closest individual and had frequent contact by the person with dementia.

- Carers who are unable to communicate in English sufficiently to participate in the interviews (as no interpreters were available for the study).

4.6 Sample size

My review found (Chapter 2) limited data available on this type of study so it was difficult to estimate a suitable sample size for this research. Therefore, I consulted a statistician (BL) for advice on sample size and power calculations. Based upon this advice, I followed their recommended general '*rule of thumb*' that a study needs to have a minimum of 15 observations (in this case dyads of PWD and their carer) per independent variable in order to ensure adequate precision of estimates in a multivariate analysis. I therefore aimed to recruit 60 participants as my research questions proposed four study outcomes (MMSE, quality of care-giving relationship, carer burden and distress).

4.7 Recruitment

All potential participants were identified by clinical team members or the dementia register lead as having a diagnosis of dementia and the mental capacity and MMSE to undertake the interview. They also made the initial approach to both the person with dementia and their carer. Once potential interest was established, I contacted each by telephone or by whatever means they indicated was preferable; e.g. email, letter etc.

Following this first contact, I sent detailed information sheets (Appendix 10 & 11) with a

covering letter on headed note paper with UCL, Dementia UK and the respective NHS Trust logos. The initial letter was brief and written in clear, simple language. It stated that I would contact them by telephone within two weeks to discuss the study further after they had had time to read the study information. They were given the choice to opt out at this stage by telephoning a dedicated number or writing a letter, in which case they were not contacted further.

Between one and two weeks after the letter and information sheets were sent, I again contacted potential participants to discuss the study and, if they wished to take part, offered an interview at a date, time and venue of their choosing. This could be at local NHS premises, the home of the person with dementia or that of the carer. If requested, a further letter confirming the interview was sent.

If potential participants were not contactable on the first occasion, they were telephoned several times to try and establish contact. Answer machine messages were avoided. Unobtainable telephone numbers were checked with the referring clinician.

4.7.1 Obtaining informed consent

At the interview appointment, dyads were given a further opportunity to ask questions regarding the study. I then carefully explained any points in the information sheets that had not been understood. Written consent was obtained directly from the both the person with dementia and their carer (Appendix 12 & 13). If, at this stage, it was apparent that either the person with dementia and or their carer did not have the mental

capacity to give informed consent (e.g. through cognitive impairment), the interview was sensitively discontinued and their demographic details recorded.

4.8 The interviews

4.8.1 The interview format

Data were collected onto paper forms. This included basic demographic data for both the person with dementia and their carer. Participating dyads were each interviewed in their place of choice. This took approximately one hour and comprised:

4.8.1.1 Person with dementia

1. Final explanation of any queries about the study and an opportunity for any final questions. This allowed a mental capacity assessment to be undertaken.
2. Consent was obtained and the documentation signed.
3. Demographic details: age, gender, ethnicity, previous education, (previous) employment, living situation i.e. with spouse, child, alone, etc.
4. Mini Mental State Examination.
5. Modified Life Support Preferences Questionnaire (LSPQ) (PWD version).
6. Quality of Care-giving Relationship (QCPR) (PWD version).

4.8.1.2 Carer of the person with dementia

1. Final explanation of any queries about the study and an opportunity for questions. This allowed a mental capacity assessment to be undertaken.
2. Consent was obtained and the documentation signed.
3. Demographic details: age, gender, ethnicity, previous education, (previous) employment, relationship to the person with dementia.
4. Zarit Burden Inventory (ZBI).
5. Kessler Psychological Distress Scale (K10).
6. Quality of Care-giving Relationship (QCPR) (carer version).
7. Modified Life Support Preferences Questionnaire (LSPQ) (Carer version).

4.8.2 Interview measures

4.8.2.1 Cognition

The Mini-Mental State Examination (MMSE) (Folstein et al., 1975, see Appendix 14) is a brief 30-item questionnaire test that is a widely used measure of cognitive function. The test includes simple questions and problems in a number of areas: orientation to time and place, repeating lists of words, arithmetic such as subtracting serial sevens, language use and comprehension, and praxis skills. Any score greater than or equal to 27 points indicates normal cognition. Below this, scores can indicate severe (≤ 9 points), moderate (10-18 points) or mild (19-24 points) cognitive impairment (Mungas, 1991).

In a review of the psychometric properties and utility of the MMSE, Tombaugh and McIntyre (1992) found its validity, when compared against gold standards (for example,

DSM-III-R and NINCDS-ADRDA criteria), fulfilled its original goal of providing a brief screening test that quantitatively assesses the severity of cognitive impairment and changes occurring over time.

I used the MMSE to ensure that all participants with dementia had a score of ≥ 20 , the rationale being that previous research suggested that this may be a realistic cut off point for capacity to engage in discussions about end of life preferences (see 2.3.4; 2.3.5 and 2.4.1).

4.8.2.2 Carer burden

The Zarit Burden Interview (ZBI) (Zarit et al., 1980; see Appendix 15) is a self-report measure of carer burden. It originated as a 29-item questionnaire which was later revised to 22 items. Each item on the interview is a statement and the carer is asked to rate how often they have experienced a feeling relating to a care issue using a five-point Likert scale. Response options range from zero (0 = never) to four (4 = nearly always).

Hébert et al. (2000) validated the ZBI in a sample of 312 carers from the Canadian Study of Health and Aging and found the measure had good internal consistency and reliability, with a Cronbach's alpha coefficient of 0.92, which was not significantly improved by the removal of any of the 22 items. Hébert et al. categorised scores to indicate levels of perceived burden which would have application in a clinical setting:

0 – 21	Little or no perceived carer burden
21 – 40	Mild to moderate perceived carer burden

41 – 60 Moderate to severe perceived carer burden

61 – 88 Severe perceived carer burden

4.8.2.3 Carer distress

The Kessler Psychological Distress Scale (K10) (Kessler et al., 2002, see Appendix 16) is a 10-item self-report questionnaire which yields a global measure of psychological distress based on questions about the level of anxiety and depressive symptoms in the preceding 4-week period. This measure was added to the interview schedule as evidence suggests that the general distress of carers of PWD should also be assessed as well as the specific burden of caring (Vitaliano et al., 1991).

Each item of the K10 is scored from one to five (1 = none of the time, 5 = all of the time). Higher scores on the K10 indicate greater psychological distress. The total score is the sum of all 10 items. Scores range from 10 – 50 with missing items excluded from the calculation of the total score.

The interpretation of the summative score indicates the presence of psychological distress:

10-19: No significant psychological distress.

20-24: Mild levels of psychological distress consistent with a diagnosis of a mild depression and/or anxiety disorder.

25-29: Moderate levels of psychological distress consistent with a diagnosis of a moderate depression and/or anxiety disorder.

30-50: Severe levels of distress consistent with a diagnosis of a severe

depression and/or anxiety disorder.

4.8.2.4 Relationship quality

The Quality of Carer Patient Relationship (QCPR) (Spruytte et al., 2002, see Appendices 17 and 18) is a 14-item scale that examines agreement on quality of the relationship between a dyad, which can include a parent and a child but also, for this purpose, carer and a care recipient. Responses are given on a 5-point Likert scale, ranging from 'totally disagree' to 'totally agree', giving a range of scores from 14 to 70, with higher values representing better relationships. The items on criticism and conflict are reverse coded, so that a higher score reflects a better relationship quality. The instrument is designed to assess the warmth of a relationship and the presence or absence of conflict and criticism.

This Dutch scale was used in my study as I wished to explore the underlying relationship between the person with dementia and their carer, rather than limit myself to examining the role of 'carer burden' in the decision making processes for end of life care. The measure has been shown to demonstrate good internal consistency in other UK studies (Woods et al., 2009; Subramaniam et al., 2014). The QCPR seeks a balanced view of the care-giving and care receiving relationship by seeking both dimensions. When considering other instruments that offer both the positive and negative dimensions they tended to be specific about their population such as spouses and their marital closeness (e.g. Van den Broucke et al., 1995) or parental attachment in child-carers (e.g. Cicirelli, 1995). As my target population was likely to include a range of carer relationships I chose the QCPR as it is of use in all carer types.

Carers and PWD were each asked to think about their present relationship with "the person you are caring for" or the "person who cares for you" and answer questions by

circling their responses.

4.8.2.5 Life support preferences

The Life Support Preferences Questionnaire (LSPQ) (Ditto et al., 2001, see Appendix 19) was constructed on the basis of extensive review of surrogate decision-making research to include nine realistic illness scenarios of varying severity, nature of impairment, prognosis, and level of pain, as follows: (i) the patient's current health, (ii) Alzheimer's disease, (iii) emphysema, (iv) coma with no chance of recovery (coma—no chance), (v) coma with a very slight chance of recovery (coma-slight chance), (vi) stroke with no chance of improvement (stroke-no chance), (vii) stroke with a very slight chance of improvement (stroke-slight chance), (viii) terminal colon cancer with no pain (cancer-no pain), and (ix) terminal colon cancer with pain that requires constant medication (cancer-pain).

The LSPQ questionnaire has not been used before in the UK, so I modified it by selecting three of the nine scenarios for this study as the primary aim was to explore the accuracy of carers' ability to predict the preferences of the person with dementia, rather than supporting the development of an advance directive. As the target population of my study already had a diagnosis of dementia scenarios, (i) and (ii) were combined to, '*as you are today, with mild memory problems*'. The two other scenarios selected were (iv) and (ix) as the scenarios involving stroke and cancer were such that most people may understand or have had experience of these conditions in family and friends. The ninth scenario was adapted to exclude the term 'colon' and include *any* terminal cancer. The modified LSPQ tool can be seen in Appendix 19.

PWD were asked to consider themselves in each scenario and indicate their preference

using a five point Likert Scale from 'definitely would want' to 'definitely would not want' for receiving three life sustaining medical treatments; antibiotics, cardio-pulmonary resuscitation and tube feeding. Carers were asked to predict what the person with dementia's treatment preferences would be in each illness scenario.

4.8.3 Data management

Each dyad was allocated a number, and the questionnaires and rating scales used were collated in paper folders only identified by the number to ensure preservation of confidentiality. The data were entered onto the Statistical Package for the Social Sciences (SPSS) spreadsheet version 21.0 (IBM, 2012) for statistical analysis. The critical activity of data checking and 'cleaning' was undertaken to ensure its accuracy.

4.9 Ethics committee and R&D approval

The study protocol was developed following a process that included both peer and carer [expert by experience] review. Ethical approval for this study was granted by the NRES Committee South East Coast – Surrey on 31st January 2012 (12/LO/0106, see Appendix 20) to undertake the interviews in Barnet, Enfield and Haringey Mental Health NHS Trust (BEH). (This was followed by a substantial amendment to include a nested, brief, qualitative semi-structured interview schedule, which is discussed in Chapter 6).

Because of changes in my employment (leaving BEH and moving to Dementia UK) and in order to enhance recruitment, various developments were necessary. Whilst the study was registered through usual NRES process, I had left NHS employment, so for

indemnity purposes the project was registered with the UCL Joint Research Office. I also obtained R&D approval to recruit and see dyads from four NHS Trusts:

- Barnet Enfield and Haringey Mental Health NHS Trust (BEH)
- Cambridgeshire and Peterborough Foundation Trust
- West London Mental Health NHS Trust
- Leicestershire and Rutland Partnership NHS Trust

Second, I obtained an honorary contract with BEH enabling me to approach PWD and their carers in the three boroughs. My honorary contract was recognised by R&D in the other three NHS Trusts as my research activities were deemed commensurate with those contracted for in BEH.

There were no ethical issues raised in relation to any of the three R&D applications.

4.10 Statistical analysis

4.10.1 Demographic data

Demographic features of the cohort were analysed using descriptive statistics. Demographic data from dyads that declined to participate were also recorded. This allowed me to assess whether consenting and non-consenting groups were demographically and ethnically comparable.

Demographic data collected included:

1. Age – Completed years – PWD and carer

Mean, median, Standard Deviation, Range (Min – Max), missing data

2. Gender – PWD and carer

Frequencies, percentages, missing data

3. Ethnicity – (self assigned) – PWD and carer

Frequencies, percentages, missing data

4. Education – Age left full time education – PWD and carer

Education up to or equal to, 14 years and education beyond 14 years;

frequencies, percentages, missing data

5. Diagnosis of dementia – ICD-10 categories for PWD

Frequencies, percentages, missing data

6. MMSE – PWD

Range of 20 – 30, missing data

7. Living situation – PWD

Frequencies, percentages, missing data

8. Relationship to PWD – carer

Frequencies, percentages, missing data

9. Standard Occupational Classification (SOC, 2010) – *based on current or last employment*

PWD and carer

Three condensed, analytical classes; frequencies, percentages, missing data

The Standard Occupational Classification (SOC, 2010) is a measure of social and economic status. I used the self-coded version of the National Statistics Socioeconomic Classification (NS-SOC) based on a combination of current or previous employment type and supervisory/managerial status. For the purposes of my study the condensed, analytic group of three categories was used:

1. Higher managerial, administrative and professional occupations
2. Intermediate occupations
3. Routine and manual occupations

And 'never worked or long-term unemployed' recorded separately. I recorded the SOC of retired people on their last occupation.

4.10.2 Carer measures

Zarit Burden Interview (ZBI)

The frequencies and percentages are reported of the levels of burden experienced by the carers of the dyads interviewed. This is derived from a total of the scores of the 22 items. A score of ≤ 20 indicates little or no perceived burden with a score of 61 – 88 indicating a severe level of perceived burden. The scores were categorised as this is common practice in the clinical situation to indicate levels of carer burden (Hébert et al., 2000, see 4.8.2.4).

Kessler Distress Scale (K10)

Similarly, the K10 total scores were added together and presented in frequencies and

percentages for each of the four categories of psychological well-being/ill-being (see Figure 4.1 and 4.8.2.3). As for ZBI, the categorisation of well-being/ill-being is common practice in the clinical situation.

Table 4.1 Levels of carer distress

	Range
Well	<20
Mild mental disorder	20-24
Moderate mental disorder	25-29
Severe mental disorder	≥30

4.10.3 Quality of Carer Patient Relationship Questionnaire (QCPR)

Spruytte et al. (2002) dichotomised their sample into ‘good’ and ‘poor’ relationships using the median of parent/carer scores, the threshold for which in their study was a score of 42. For the purposes of my study, I wished to take into account the views of the PWD as well as the carers, so I used the median score from all the values supplied by PWD and carers, in order to create two categories of ‘good’ and ‘poor’ relationships. The median score by this means was 60, so a dyad was counted as being in the ‘good’ relationship category if either the PWD or the carer achieved a score of 60 or above.

4.10.4 Preferences for end of life care: the modified Life Support Preferences Questionnaire (LSPQ)

As stated earlier (see 4.3) my first research question was that:

PWD and their family carers agree on life sustaining medical treatments at the

end of life care.

To test this, I examined agreement for life sustaining medical treatments between PWD and their carers using the modified LSPQ. Following past research (Uhlmann et al., 1988; 1989; Seckler et al., 1991; Fagerlin et al., 2001; Sharmon et al., 2008), I created indices using both the full five-point scale and a dichotomized scale indices collapsing 'definitely want', 'probably want', and 'unsure' responses into a *want treatment* category, and 'definitely don't want' and 'probably don't want' into a *don't want treatment* category. I categorized 'unsure' responses with 'want treatment' responses because in most instances the clinical default is to provide treatment unless it is specifically refused personally or in an advance decision to refuse treatment: Thus, assigning a value of zero for 'do not want treatment' and one for 'want treatment':

0. Do not want treatment (collapsing 'probably do not want' and 'Definitely do not want').
1. Would want treatment (collapsing 'definitely want treatment', 'probably want treatment' and 'unsure')

The first analysis undertaken was agreement between the person with dementia and their family carer on the modified LSPQ. Three of the nine scenarios were selected and results were examined in 2x2 tables and characterised using percentage agreement and the kappa coefficient (Cohen, 1960). Cohen's kappa (k) coefficient is a statistical measure of inter-rater agreement for (categorical) items. It is generally thought to be a more robust measure than simple percent agreement calculation since

k takes into account the agreement occurring by chance. Kappa was applied to all scenario and treatment calculations. It has a maximum of one when agreement is perfect, zero when agreement is no better than chance, and negative values when agreement is worse than chance. Kappa is a useful technique but given imbalanced agreement matrices, it can yield unexpected results. If the prevalence index is high (i.e., the prevalence of a positive rating is either very high or very low), chance agreement is also high and kappa is reduced accordingly. Thus, as the level of agreement was particularly high, especially in scenario one, this imbalanced the Kappa measure. This has been found to be so in other studies using Kappa (O'Leary et al., 2013). The Prevalence and Bias Adjusted Kappa (PABAK) measure was also applied to all calculations and adjusts the Kappa imbalances caused by the differences in the prevalence and bias (Byrt et al., 1993). PABAK is also an index of inter-rater agreement which controls for chance agreement. Chen et al. (2009) recommend that both Kappa and PABAK data is presented along with percentages of agreement/disagreement to enable the reader to judge the validity of data from multiple aspects.

Several statisticians have sought to identify indices to categorise strength of level of agreement using Kappa (Landis and Koch, 1977; Altman, 1991; Fleiss et al., 2003), however there is no similar evidence for representing PABAK similarly, though several studies refer to good levels of agreement using PABAK as 0.7 or have applied similar levels of agreement to those identified in Kappa (Schoutman et al., 2005; Wardle et al., 2009; Gupta et al., 2012). For the purpose of this study I have used the indices as used by Fleiss et al. (2003) (Fleiss et al., 2003, see Table 4.2) and have used this also as an indicator of level of agreement for PABAK also.

Table 4.2 Strength of agreement

Kappa statistic	Strength of Agreement
0.81 – 1.00	Very good
0.61 – 0.80	Good
0.41 – 0.60	Moderate
0.21 – 0.40	Fair
< 0.20	Poor

The results will also be reported as the average number of items on which carer and person with dementia made the same decision. As in other studies (Fagerlin et al., 2001), for each set of nine judgments (three treatments in the three health scenarios) I will categorise dyads as to whether they have a good level of agreement (7-9 items), moderate agreement (4-6 items) or low agreement (0-3 items).

4.10.5 Factors that influence agreement

As may be recalled, my second research question was that:

Good care-giving relationships and lower levels of perceived carer burden improve agreement on life sustaining medical treatments at the end of life.

To investigate this I conducted univariate tests comparing the demographic characteristics of carer participants who were in agreement and those not in agreement with each item on the modified LSPQ. I compared the mean scores of the proposed

influencing factors, i.e. MMSE, carer burden and distress and quality of carer patient relationship, between the agreement and no-agreement groups, using t-tests or Mann-Whitney tests, as appropriate. For categorical variables I used Chi squared tests.

4.10.5.1 Factors that influence a carers ability to predict treatment preferences

As Admiral Nurses' clinical focus is with family carers of PWD, the second research question was concerned with examining if there was a relationship between a carer's ability to predict the treatment preferences of the PWD and the *actual* preferences of the PWD. Therefore, using the modified LSPQ data, I developed a 'prediction index' to reflect carers' levels of accurate prediction. Where a carer was accurate in a treatment prediction of the person with dementia, whether that was for active treatment or not, they gained a score of one. Uncertainty only achieved a score of one if that also predicted uncertainty for the treatment preference of the person with dementia. Thus, using the three health scenarios of the modified LSPQ and three treatment options for each, there was a possible score of 0 – 9; 0 = no ability to predict through to 9 = full ability to predict treatment preferences. Combining scores from all carers gave an overall indication of level of prediction in the sample.

Finally, I undertook further analyses using multiple linear regression to explore the relationship between ability to predict treatment using the 'prediction indices' and carer factors. Therefore, I used the modified LSPQ prediction index as the dependent/outcome variable to explore the likelihood of a potential relationship with the independent/predictor variables: relationship to the PWD, quality of carer patient relationship (QCPR), perceived carer burden (ZBI) and psychological distress (K10).

4.10.6. Missing values

The number of missing values for each demographic characteristic and variable are reported in Chapter 5. For questionnaires such as the K10 and ZBI, missing data were completed by mean imputation (Huisman, 2000). Imputation preserves all cases by replacing missing data with a probable value based on other available information (Raghunathan et al., 2001). Its main disadvantage is that it reduces variability in this data and therefore may produce overly precise estimates of association. Multiple imputation techniques have been developed to overcome this drawback. However, this is complex to undertake and is preferable in larger data sets where there are many co variables that can be used to predict missing values. Shrive et al. (2006) compared six different strategies of imputation and found that, where less than 10% of values were missing, single imputation of the mean value of other data is an appropriate and simple method that produces favourable results.

5.0 Results

5.1 Recruitment

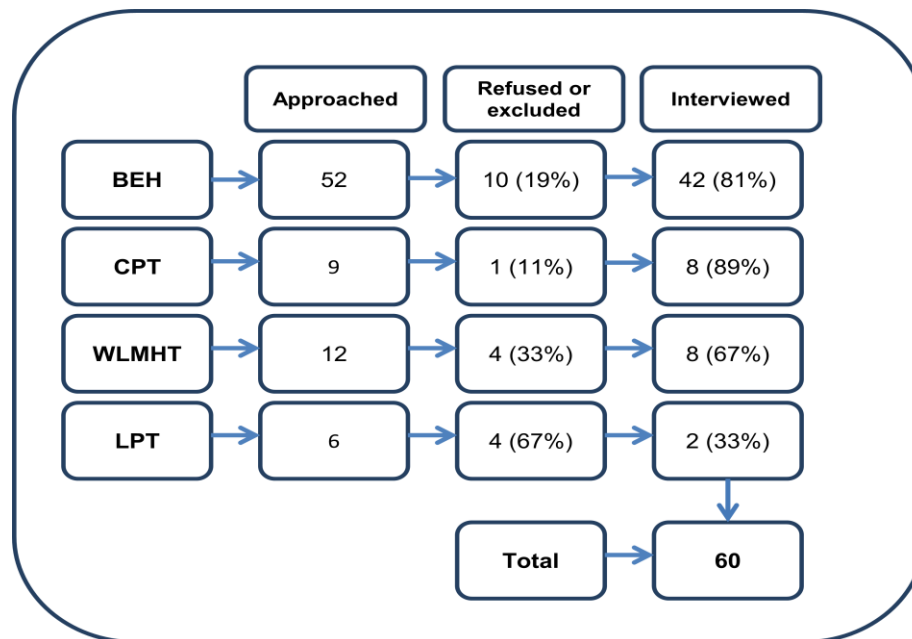
Recruitment commenced in Barnet Enfield and Haringey Mental Health NHS Trust in April 2012 (Table 5.1). As recruitment was slow (n = 12 dyads by the end of July 2012), R&D approval was gained at three further sites; Cambridgeshire and Peterborough Foundation Trust, West London Mental Health NHS Trust and Leicestershire Partnership NHS Trust. Recruitment finally ended in February 2014 having reached a total of 60 dyad interviews (Table 5.1).

Recruitment was higher in BEH (n = 42) due to several factors. First, I was clinically associated with BEH at the outset of my research, thus BEH was the primary site, and I attended clinical team meetings to assist recruitment. Second, BEH were developing a register of PWD and family carers interested in participation in research. West London Mental Health Trust also allowed me access to their dementia research register which yielded eight dyads.

Table 5.1 Recruitment from April 2012 to February 2014

		April 2012	May 2012	June 2012	July 2012	August 2012	September 2012	October 2012	November 2012	December 2012	January 2013	February 2013	March 2013	April 2013	May 2013	June 2013	July 2013	August 2013	September 2013	October 2013	November 2013	December 2013	January 2014	February 2014
Dyads recruited	7																							
	6																							
	5																							
	4																							
	3																							
	2	2	3	1	5	6	4	4	4	2	4	2		5	2	2	5		2	3				
	1																							1
Dyads refused	1			1	1			1		1			1		1	1	1	1	1	1	1	1	1	
	2			1				1				1	1			1	1	1	1	1	1	1	1	
	3																							
	4																							
	5																							
	6																							
	7																							

Figure 5.1 Recruitment across the four sites



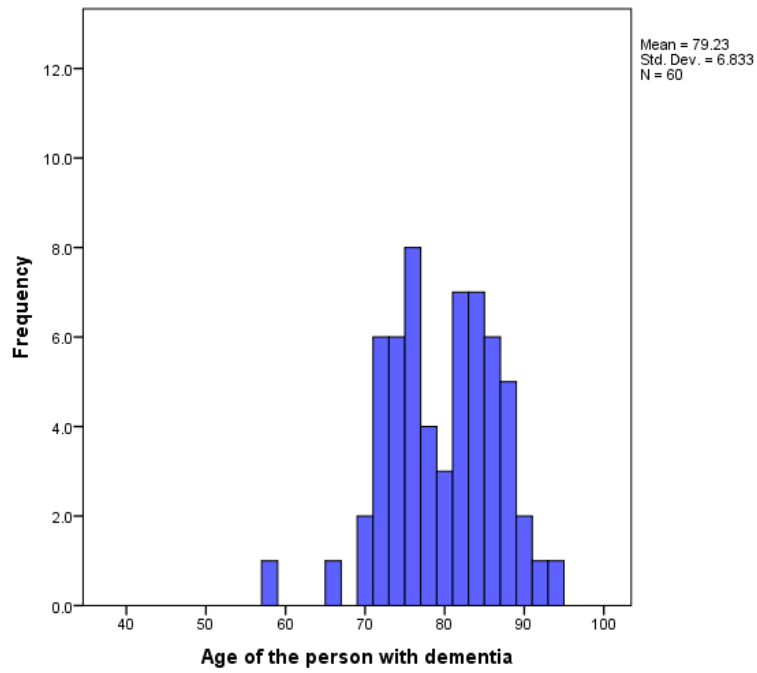
5.2 Non participation

Of the 79 dyads approached in the four sites, 17 (22%) declined participation (Figure 5.1) and two (12%) were excluded as the person with dementia did not meet the inclusion criteria at interview (one lacked the capacity to give informed consent and one had an MMSE score of less than 20). The commonest reason for refusal to participate was the carer declining on behalf of the dyad due to their own level of 'stress' (n = 8, 47%). Three PWD (18%) did not want to undertake research in the field of end of life preferences, so excluding their carer's involvement. Other reasons given were: wanted drug trials only (n = 1, 6%), saw no benefit to themselves in involvement (n = 1, 6%) and no reason given (n = 2, 12%).

5.3 Participant demographic characteristics

The age range of PWD (Table 5.2) was 58 to 93 years with a mean age of 79.2 years (SD6.8) with normal distribution (Figure 5.2).

Figure 5.2 Age distribution of PWD.



The age range of carers was 39 to 93 years with a mean age of 66.6 years (SD 12.8) (Figure 5.3). The distribution is bi-modal, this is as expected given the mix of spouse and adult children carers.

Figure 5.3 Age distribution of carers.

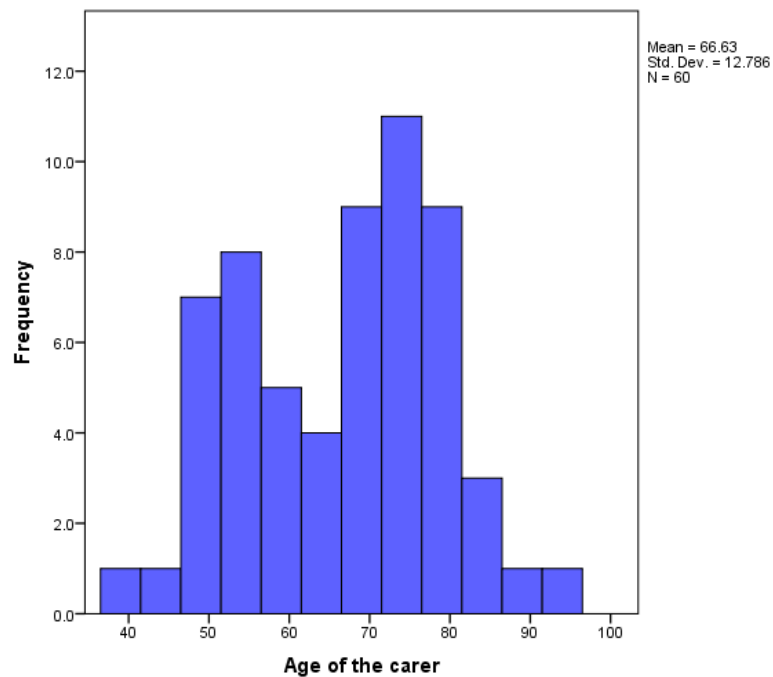


Table 5.2 Characteristics of dyads (n = 60)

	PWD (n = 60)	Carers (n = 60)
Age (mean (SD) [range])	79.2 (6.8) [58-93]	66.6 (12.8) [39-93]
Gender (% male)	26 (43%)	19 (32%)
MMSE (mean (SD) [range])	25.4 (2.4) [20-29]	
Diagnosis (ICD 10)		
F00.1 (Alzheimer's late onset)	40 (67%)	-
F00.2 (atypical or mixed type Alzheimer's)	12 (20%)	-
other	8 (13%)	-
Ethnicity		
White British	38 (63%)	42 (70%)
White other*	16 (27%)	12 (20%)
Other**	6 (10%)	6 (10%)
Previous education		
Left school ≤ 14 years	14 (23%)	5 (8%)
Left school ≥ 15 years	46 (77%)	55 (92%)
Living situation of PWD		
Alone	14 (23%)	-
Spouse/partner	37 (62%)	-
Other	9 (15%)	-
Relationship to PWD		
Spouse	-	35 (58%)
Adult child	-	18 (30%)
Other	-	7 (12%)
Employment - SOC 2010		
1. Higher managerial, administrative and professional qualifications	28 (47%)	31 (52%)
2. Intermediate occupations	15 (25%)	18 (30%)
3. Routine and manual occupations	16 (27%)	9 (15%)
Never worked or long-term unemployed	0	1
Missing	1	1

Note: PWD = Person with dementia. MMSE = Mini Mental State Examination. ICD 10 = International Disease Classification. SOC = National Statistics Standard Occupational Classification.

* White other includes Irish, Jewish, Greek Cypriot, Turkish Cypriot, Polish and Russian.

**African Caribbean, Indian and Bangladeshi.

The MMSE scores of PWD (n = 60), on a scale of 0-30, ranged from 20 to 29/30.

The mean value was 25.4 (SD 2.4) (Figure 5.4). The lower score of 20/30 was dictated by the inclusion criteria, whilst those PWD with scores of 25 and above may

be attributed to higher levels of education and an active memory clinic.

Figure 5.4 MMSE score distribution

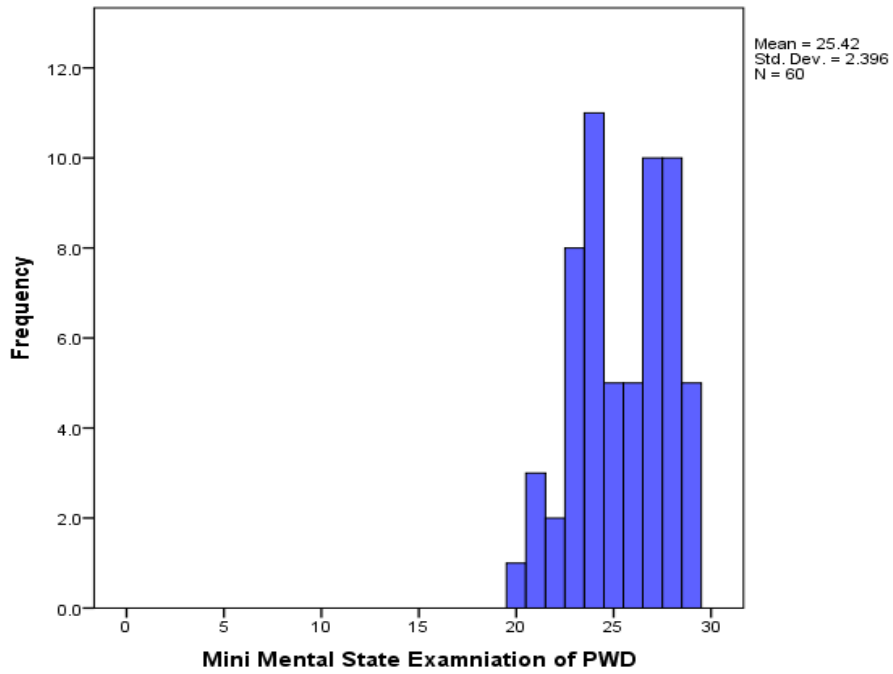
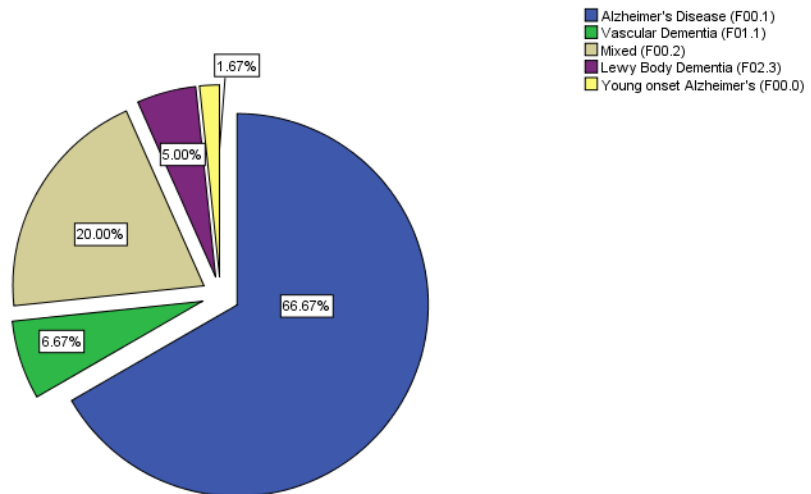


Figure 5.5 Dementia diagnosis of PWD



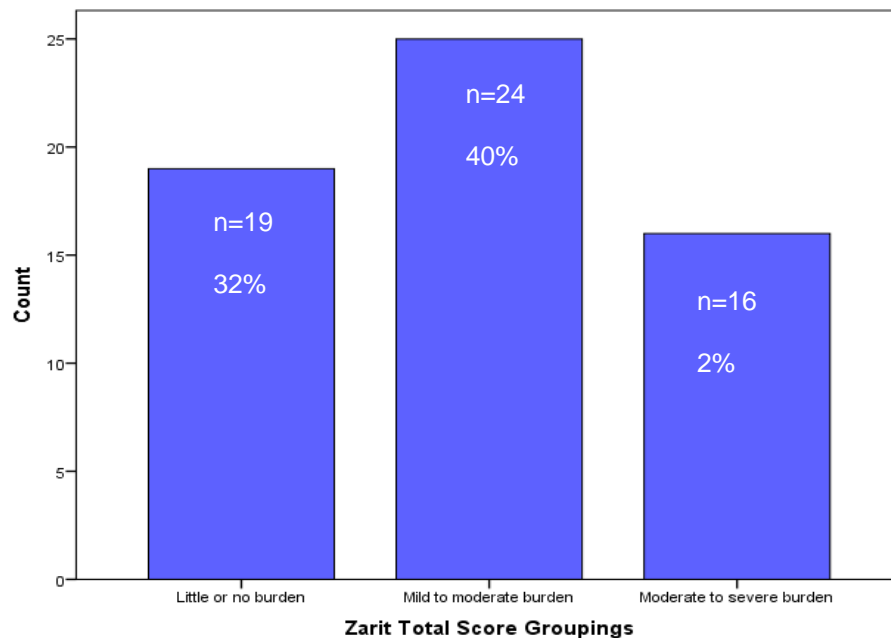
5.4 Carer and relationship measures:

5.4.1 Carer burden

Most carers (n = 59, 98%) completed the Zarit Burden Interview to indicate their perceived level of burden (see 4.8.2.2). There was only one set of carer data missing which was imputed. Scores which reflected how often the carer felt burdened by various aspects of caring for a person with dementia, were added to provide a total for each individual. Individual carer scores ranged from five ('little or no burden') to 70 ('severe burden').

Almost a third of carers (n = 19, 31.7%) perceived 'little or no burden'. The largest proportion of carers (n = 24, 40%) perceived 'mild to moderate burden' with 16 (26.7%) carers feeling 'moderate to severe burden'. Including one carer who rated their burden as severe on most aspects of the ZBI (Figure 5.6).

Figure 5.6 Zarit Burden Interview: Grouping of scores

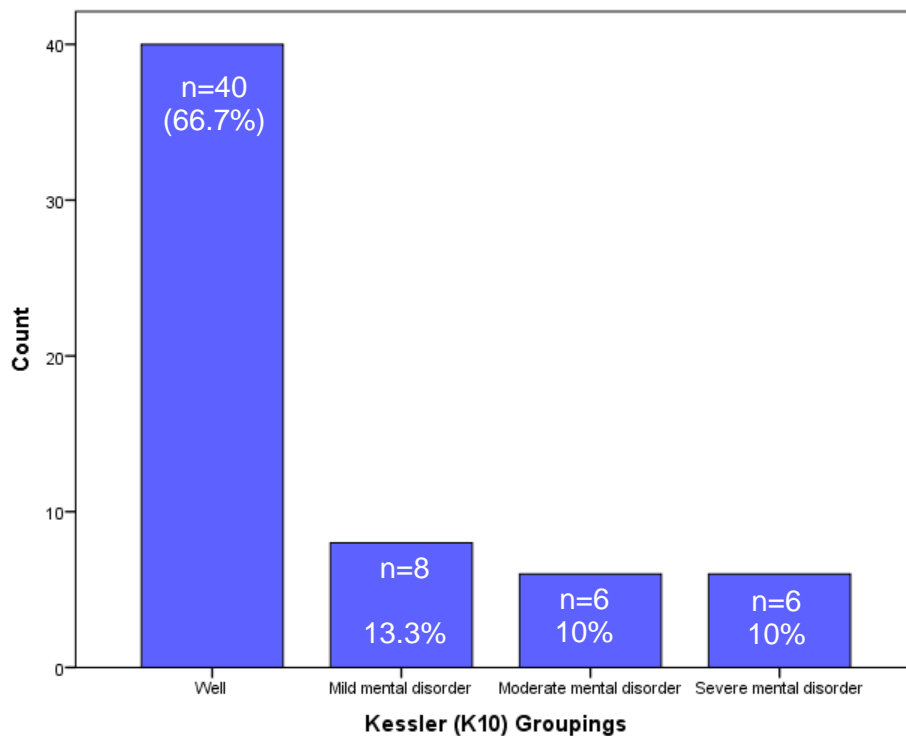


5.4.2 Carer distress

The Kessler Psychological Distress Scale (K10) (see 4.8.2.3) indicates the level of psychological distress experienced by carers in the 4-week period prior to interview (minimum score 10, maximum score 40). The mean score in my sample was 18.8 (SD 7.38) with a median of 16.0 and scores ranging from 10-39. Missing data were imputed.

Data from individual scores were then grouped and assigned a categorical score dependent upon levels of perceived psychological distress, as defined by the authors of the measure (Figure 5.7). The majority of carers fell within the range defined as 'well' (score <20; n = 40, 66.7%). Eight (13.3%) were defined as having a 'mild mental disorder' (score = 20-24), six (10%) as having a 'moderate mental disorder' (score = 25-29), and six (10%) a 'severe mental disorder' (score ≥ 30).

Figure 5.7 Kessler Psychological Distress Scale: Grouping of carers' scores

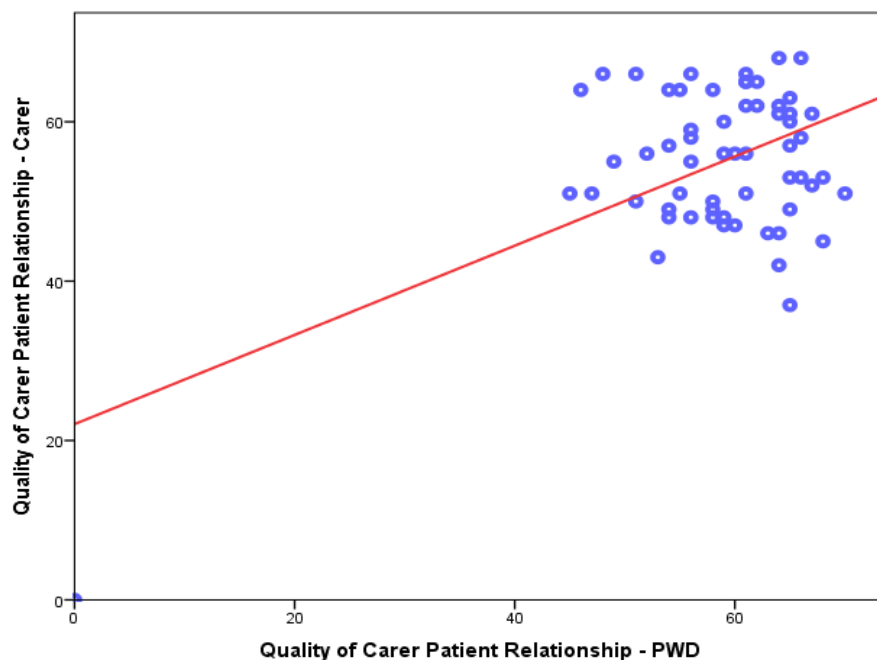


5.4.3 Quality of relationship

The Quality of Carer Patient Questionnaire (QCPR) was completed both by PWD (n = 60, 100%) and carers (n = 59, 98%). One carer did not complete the scale, thus as one whole set of QCPR data was missing, this was not imputed but recorded as a missing value.

There was no statistically significant association between the quality of the relationship as perceived by the PWD and by carers (Pearson's $r = 0.048$; $P = 0.718$), as shown in the scatter plot in Figure 5.8.

Figure 5.8 Quality of Carer Patient Relationship



As mentioned in 4.8.2.4 I used the median score from all the values supplied by PWD and carers, in order to create two categories of 'good' and 'poor' relationships. As the data were unevenly distributed, the median score by this means was 56, so a dyad was counted as being in the 'good' relationship category if either the PWD or the carer achieved a score of 56 or above. By dividing the score of the QCPR data at the threshold of 56, I created two categories: those with a 'poor' relationship (n =

32 dyads, 53%) and those with a 'good' relationship (n = 27, 45%).

5.4.4 The preferences of PWD and their carers

The modified Life Support Preferences Questionnaire (LSPQ) was completed both by PWD (n = 60) and carers (n = 59) (Tables 5.3). One carer did not complete the scale; as one whole set of LSPQ data was missing, this was not imputed but recorded as a missing value. Data are presented as the treatment preferences for active or non active treatment (Table 5.3) and the carers' ability to predict these.

5.4.5 Active versus no active treatment

The preference for active or non active treatment preferences arising from the modified LSPQ data was described; both in respect of the preferences of the person with dementia and the prediction of these by the carer (Table 5.3).

5.4.6 Modified LSPQ, Scenario One ('as you are today')

In scenario one, most PWD (n = 59, 98%) expressed a preference for active treatment for antibiotics. However, the preference for active treatment was lower in other treatment options: CPR (n = 53, 88%) and tube feeding (n = 39, 65%). Carer predications for active treatment were similar in scenario one (n = 56, 93%) but decreased in future scenarios and the treatment options of CPR (n = 49, 82%) and tube feeding (n = 30, 50%).

5.4.7 Modified LSPQ, Scenario Two (severe stroke and coma)

In scenario two, about half the PWD showed a preference for no active treatment (antibiotics, n = 30, 50%; CPR, n = 34, 57%; tube feeding, n = 30, 50%) (Table 5.3).

Table 5.3 Preferences for active versus no active treatment

Modified LSPQ	PWD Preference for active treatment	Carer Estimate of PWD's preference for active treatment
Scenario 1 'As you are today'		
1(a) antibiotics		
Want active treatment	59 (98%)	56 (93%)
Do not want active treatment	1 (2%)	3 (5%)
Not sure	-	-
Missing	-	1 (2%)
1(b) CPR		
Want active treatment	53 (88%)	49 (82%)
Do not want active treatment	6 (10%)	8 (13%)
Not sure	1 (1%)	2 (3%)
Missing	-	1 (2%)
1(c) Tube feeding		
Want active treatment	39 (65%)	30 (50%)
Do not want active treatment	13 (22%)	19 (32%)
Not sure	8 (13%)	10 (16%)
Missing	-	1 (2%)
Scenario 2 'Severe stroke and coma'		
2(a) antibiotics		
Want active treatment	28 (47%)	17 (28%)
Do not want active treatment	30 (50%)	40 (67%)
Not sure	2 (3%)	2 (3%)
Missing	-	1 (2%)
2(b) CPR		
Want active treatment	20 (33%)	10 (17%)
Do not want active treatment	34 (57%)	44 (73%)
Not sure	6 (10%)	5 (8%)
Missing	-	1 (2%)
2(c) Tube feeding		
Want active treatment	23 (38%)	16 (27%)
Do not want active treatment	30 (50%)	40 (66%)
Not sure	7 (12%)	3 (5%)
Missing	-	1 (2%)
Scenario 3 'Advanced cancer'		
3(a) antibiotics		
Want active treatment	28 (47%)	33 (55%)
Do not want active treatment	25 (42%)	20 (33%)
Not sure	7 (12%)	6 (10%)
Missing	-	1 (2%)
3(b) CPR		
Want active treatment	18 (30%)	19 (31%)
Do not want active treatment	36 (60%)	36 (60%)
Not sure	6 (10%)	4 (7%)
Missing	-	1 (2%)
3(c) Tube feeding		
Want active treatment	22 (37%)	22 (37%)
Do not want active treatment	31 (51%)	34 (56%)
Not sure	7 (12%)	3 (5%)
Missing	-	1 (2%)

Notes: PWD = Person with dementia, CPR = Cardio Pulmonary Resuscitation.

Whilst carers were able to predict this preference shift of the PWD towards no active treatment, they tended to overpredict this desire (antibiotic, n = 40, 67%; CPR, n = 44, 73%, tube feeding, n = 40, 66%).

5.4.8 Modified LSPQ, Scenario Three (Advanced cancer)

In scenario three, PWD were slightly more in favour of antibiotic treatment (n = 28, 47%) than other treatment options (CPR, n = 18, 30%; tube feeding, n = 22, 37%). As for scenario two, the majority chose no active treatment for all three options.

Carers predictions of the PWD's preference for active treatments were very similar (antibiotics, n = 33, 55%, CPR, n = 19, 31%; tube feeding, n = 22, 37%) (see Table 5.3).

5.5 Agreement between the person with dementia and their carer

The section above has presented data for the whole group but we need to examine more closely the predictions about future health treatments made by carers on behalf of PWD. I will do this first, in this section, by measuring inter-rater reliability by means of kappa and adjusted kappa, and later by looking at agreement within individual dyads.

5.5.1 Modified LSPQ, Scenario One ('as you are today')

In the LSPQ scenario one, 'as you are today', the ability of the carer to predict the treatment choices of the person with dementia was generally high when compared to scenarios two and three (Table 5.4). Agreement on preference for antibiotic treatment was the highest level of agreement of all treatment options in all scenarios

at 71% ($k = 0.03$; PABAK = 0.4, $P = 0.005$). In scenario one, the treatment of tube feeding revealed a poor, non-significant level of agreement above what would be expected by chance, 20% ($k = -0.02$; PABAK = -0.60, $P = 0.61$, NS).

5.5.2 Modified LSPQ, Scenario Two (severe stroke and coma)

In LSPQ scenario two, imagining a 'severe stroke and coma' in the future, the ability of carers to predict the treatment choices of the persons with dementia was lower than in scenario one. In the choice of antibiotic treatment the strength of agreement (Table 5.4) was defined as 'poor' with 22% ($k = -0.022$; PABAK = -0.60, $P = 0.62$, NS). There was a 42% level of agreement in the choice of CPR ($k = 0.20$; PABAK = -0.20, $P = 0.006$). Carers were able to predict the treatment choice of tube feeding with a 44% degree of accuracy ($k = 0.25$; PABAK = -0.12, $P = 0.002$).

5.5.3 Modified LSPQ, Scenario Three (advanced cancer)

In LSPQ scenario three where the dyad were asked to imagine the scenario of 'advanced cancer with six months to live', the level of agreement for antibiotic treatment was just only 24% which was rated poor on both Kappa and PABAK measures ($k = -0.03$; PABAK = -0.52, $P = 0.32$, NS) (Table 5.4). For CPR agreement was also low at 27% but with only 'poor' reliability indicated ($k = -0.07$; PABAK = -0.45, $P = 0.83$, NS), this showed no significance of $P=0.830$. Agreement for tube feeding was 39%, however this was only a 'low' strength (see Tables 5.4 and 5.5) using Kappa and PABAK ($k = 0.20$; PABAK = -0.22; $P = 0.0009$).

Table 5.4 Modified Life Support Preferences Questionnaire – Agreement

LSPQ Scenario	% Agreement	% Expected agreement	Kappa (<i>k</i>)	PABAK	P
Scenario 1 ‘As you are today’					
1a Antibiotics	71.2	59.4	0.34	0.42	0.005
1b CPR	62.7	45.2	0.30	0.30	0.0002
1c Tube feeding	20.3	22.0	-0.0184	-0.60	0.610
Scenario 2 ‘Severe stroke and coma’					
2a Antibiotics	22.0	24.0	-0.022	-0.60	0.623
2b CPR	42.4	30.0	0.21	-0.20	0.006
2c Tube feeding	44.1	26.0	0.25	-0.12	0.002
Scenario 3 ‘Advanced cancer’					
3a Antibiotics	24.0	21.4	0.03	-0.52	0.324
3b CPR	27.1	32.0	-0.07	-0.45	0.830
3c Tube feeding	39.0	23.4	0.20	-0.22	0.0009

Note: LSPQ = Life Support Preferences Questionnaire; PWD = Person with dementia; PABAK = Prevalence And Bias Adjusted Kappa; CPR = cardio pulmonary resuscitation.

Table 5.5 Strength of agreement (Fleiss et al., 2003)

Kappa statistic	Strength of Agreement
0.81 – 1.00	Very good
0.61 – 0.80	Good
0.41 – 0.60	Moderate
0.21 – 0.40	Fair
< 0.20	Poor

5.5.4 Uncertainty

When either the person with dementia or the carer expressed a level of *uncertainty* by choosing the ‘unsure’ response on the modified LSPQ, this was potentially lost in the way the modified LSPQ scores were later dichotomised and analysed (see section 4.10.3). Therefore in this section I examine this separately (Tables 5.6 and

5.7). As described in section 4.10.3, in order to measure agreement more simply, ‘definitely want’ and ‘probably want’, and ‘unsure’ responses were merged into a *want treatment* category (value 0), and ‘definitely don’t want’ and ‘probably don’t want’ into *don’t want* category (value 1). I categorised ‘unsure’ responses with ‘want treatment’ responses because in most instances treatment is provided unless it is refused face to face or in an advance decision.

When considering scenario one (‘as you are today’) there was no uncertainty in the first treatment choice, antibiotics: the vast majority of PWD wanted this treatment and their carers accurately predicted this. However, uncertainty became more common for treatments of CPR and tube feeding, with carers having a 3% degree of uncertainty as to whether they would predict CPR and 16% in considering tube feeding (Table 5.7).

Table 5.6 Uncertainty of PWD for life sustaining treatment

Treatment	Scenario 1 As you are today	Scenario 2 Severe stroke and coma	Scenario 3 Advanced cancer	Total
a) Antibiotics	0	2 (3%)	7 (12%)	9 (15%)
b) CPR	1 (1%)	6 (10%)	6 (10%)	13 (22%)
c) Tube feeding	8 (13%)	7 (12%)	7 (12%)	22 (37%)
Total	9 (15%)	15 (25%)	23 (35%)	

Table 5.7 Uncertainty of carers’ estimates of PWD’s preferences for life sustaining treatment

Treatment	Scenario 1 As you are today	Scenario 2 Severe stroke and coma	Scenario 3 Advanced cancer	Total
d) Antibiotics	0	2 (3%)	6 (10%)	8 (14%)
e) CPR	2 (3%)	5 (8%)	4 (7%)	11 (19%)
f) Tube feeding	10 (16%)	3 (5%)	3 (5%)	16 (27%)
Total	12 (20%)	10 (17%)	13 (22%)	

There was a degree of uncertainty in carers being able to predict the treatment choices of the person with dementia. Higher levels of uncertainty were evident within all treatment choices of scenario three, 'terminal cancer with six months to live' (Table 5.7).

Overall there was a greater degree of uncertainty surrounding the tube feeding treatment option in both carers' estimates of the PWD's preferences (n = 16, 27%) and PWD's preferences themselves (n = 21, 35%).

5.6 Carers ability to predict treatment preferences of the PWD

The main risks inherent in making multiple comparisons, such as those which have just been described, is that findings may occur by chance and none are adjusted for the influence of other possible explanatory or confounding variables. Thus, I calculated an overall measure of carers' estimation of the PWD's preferences for use in a multivariate analysis. Using the modified LSPQ data, I developed a 'prediction index' as a measure of overall accuracy of prediction across the scenarios. All dyad response was scored according to their agreement on the questions posed in the modified LSPQ interview schedule (see 4.10.5.1), thus, each carer was scored on their ability to predict treatment preferences of the PWD on a scale of one to nine.

Where a carer indicated they were 'unsure' yet the PWD with dementia had made a clear preference, this was seen as an inability to predict. If both the carer and the PWD were unsure about a treatment this was seen as an ability to predict, albeit they were predicting uncertainty. Combining scores of all carers gave an overall indication of level of prediction in the carer sample; the mean value was 5.53 (SD

2.003, range 1-9) with one missing value. Data was of a normal distribution (Figure 5.9).

This index was used to purposively sample dyads for nested, qualitative interviews (see 6.5.2).

Figure 5.9 Modified LSPQ – Index of carer prediction

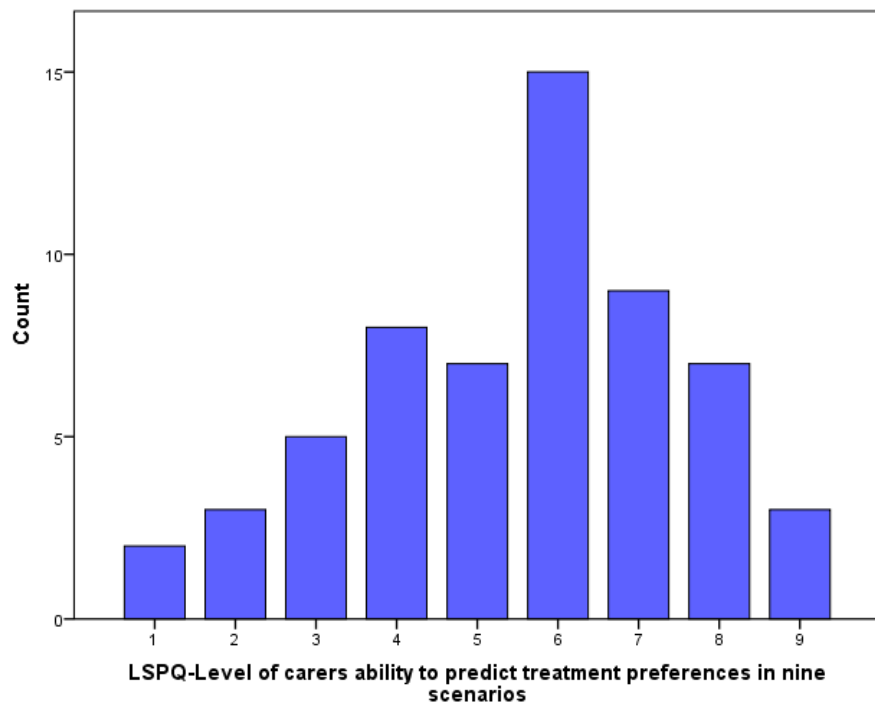


Table 5.8 Modified LSPQ - Level of carer ability to predict treatment preferences

Life Support Preferences Questionnaire	
Score	Level of prediction
1 - 3	Low ability to predict
4 - 6	Moderate ability to predict
7 - 9	High ability to predict

5.7 Association between demographic data and life support preferences

On an exploratory basis I conducted a series of univariate analyses looking at the relationships between the modified LSPQ and other variables. There were no statistically significant influences of such factors as age and gender of PWD or carer, nature of their relationship, living arrangements or MMSE of the PWD.

5.8 Association between carer measures and life support preferences

There were no significant associations between the quality of the carer patient relationship (QCPR), carer burden (ZBI) or carer distress (K10) and agreement or disagreement on the modified LSPQ (see Tables 1, 2 and 3, Appendix 21). Within the three tables there was only result that was statistically significant; however, this is likely to be a spurious chance finding.

5.9 Modified LSPQ and carer variables - Multiple linear regression

Multiple linear regression was used to explore the association between the modified LSPQ prediction index (outcome/dependent variable) and the independent (predictor) variables of relationship to the person with dementia, quality of the carer patient relationship (QCPR), perceived carer burden (ZBI) and psychological distress (K10). As shown in Table 5.10, none of these analyses revealed any significant association between the variables examined.

Table 5.9 Modified LSPQ and carer variables – Multiple linear regression

	B	95%		Sig.
		Confidence Interval		
		Lower	Upper	
(Intercept)	5.691	.642	10.740	.027
Relationship - Other	.566	-1.194	2.326	.529
Relationship – Adult child	.846	-.358	2.050	.168
Relationship - Spouse	0 ^a	.	.	.
QCPR	.009	-.070	.088	.825
ZBI	-.004	-.055	.048	.893
K10	-.048	-.139	.042	.296

Note: LSPQ = Life Support Preferences Questionnaire; QCPR = Quality of Carer Patient Relationship; ZBI = Zarit Burden Interview; K10 = Kessler Psychological Distress Scale.

5.10 Summary of findings

Findings relating to the sample demographics

- Participants tended to be of White British origin and have spent more time in education.
- Most PWD lived with their spouse/partner.

Findings relating to carer burden and distress

- Almost half of carers perceived a mild to moderate degree of carer burden.
- Just over two thirds of carers experienced mild or no psychological distress, however, the remainder were spread across moderate and severe psychological distress.

Perceived quality of carer patient relationship

- There was a high level of mutual satisfaction in the relationship between the PWD and carers on the QCPR.

Uncertainty in treatment preferences

- There was a high level of uncertainty for PWD and carer in making treatment preferences for future scenarios, particularly CPR and tube feeding.

Dyadic agreement and the ability of carers to predict treatment preferences of the PWD

- There was no evidence that factors such as perceived carer burden, and quality of carer patient relationship affected prediction of future treatment choices.
- Carers with higher levels of psychological distress tended to disagree with the treatment preference of the PWD for antibiotics in severe stroke and coma.
- Carers showed a better ability to predict the treatment preferences of the PWD in 'the here and now'.
- The ability of carers to predict the treatment preferences of the PWD in future scenarios was moderate to low.

5.11 Discussion

5.11.1 Demographic data

The age distribution of PWD was normal with a range that would be expected within an older population (Ziegler-Graham et al., 2008). There was just one person of working age who had dementia (age 59 years). The distribution of carer age was bi-modal which is as would be expected given the different types of carer relationship in the sample; spouses and adult children and their respective age differences. The majority of PWD had a diagnosis of Alzheimer type, of late onset (ICD-10, code F00.1) which is consistent with epidemiological data (Fratiglioni and Qiu, 2013).

There was a higher proportion of females in my study sample, both in PWD (57%) and their carers (68%). This would be expected, as higher prevalence and incidence rates of dementia have been reported in women than in men in cross sectional studies (Fratiglioni and Qiu 2013). Females more readily survive into older age than men; however, Fratiglioni and Qiu argue that this may also be due to different mechanisms, for example, men who survive to advanced years may have characteristics which lower their risk of developing dementia. The higher proportion of females in the sample is also consistent with findings in other studies in this field, found during my systematic review (Hirschman et al. 2004, 2008; Lingler et al. 2008; Triplett et al. 2009). Most family carers are female, frequently wives, with also high numbers of daughters as carers (Gallicchio et al., 2002). This is due to demographics and socio-cultural factors; women have longer life expectancy as well as an expectation that they accept a social role as carers (Schneider et al., 1999).

Whilst the sample overall is represented by a range of different ethnicities, most participants were of white British origin, which is consistent with other studies in this field (Fazel et al., 1999, 2000; Gregory et al., 2007). The study sample is thus not wholly reflective of the ethnic profiles of each of the four sites populations which varied from an 91% white British population in Rutland to 35% white British in Haringey¹⁵. However, as I had no funding for language interpreters, this may have reduced the potential to recruit participants various minority ethnic groups.

More carers, especially adult children, had gone on to higher education compared with the PWD. This reflects the national trend for subsequent generations to have greater access to further education (HESA, 2007/2008). This is consistent with findings of other studies revealed in the systematic review in that samples tend to show those with higher education are more likely to agree to participate in studies of

¹⁵ <http://www.ons.gov.uk/ons>

this kind (Fazel et al. 1999, 2000; Lingler et al. 2008; Hirschman et al. 2004, 2008).

In occupational grouping (National Statistics Socioeconomic Classification), almost 50% of PWD and their carers fell into the higher managerial, administrative and professional occupational category and, showing a high level of attainment in occupation across both groups. Ko et al. (2014) also found that, among other factors, participants in higher occupational categories and with higher incomes were more likely to engage in advance care planning and research than their lower paid and employed counterparts.

5.11.2 Descriptive data of study variables

Most carers perceived themselves as having mild to moderate levels of burden on the ZBI (4.8.2.4). Numerous studies have examined carer burden in the context of dementia (1.8.5). Some of these studies have examined perceived carer burden across the trajectory of dementia and looked at which factors predicted the degree of burden (Conde-Sala et al., 2014). However, other studies have demonstrated similar levels of perceived burden in carers of those with other long term illnesses (De Korte-Verhoef et al. 2014; Sautter et al. 2014). Costa-Requena et al. (2014) also found that levels of carer burden increase towards the end of life, irrespective of the disease group. However, my study focused on the role of carer burden in the degree to which carers could accurately predict the PWD's preferences for care across the scenarios tested.

Carer distress was measured using the Kessler Psychological Distress Scale (4.8.2.3), another self-rated measure. The data revealed a skewed distribution, with the majority of carers rating themselves as being mentally well. However, a third of carer participants did indicate some levels of psychological distress. Whilst much is already known about patient factors that directly generate distress in family carers,

such as behaviours and declining function (Fauth and Gibbons, 2014), recent research has shown that carer psychological distress and depression are also themselves predictors of perceived carer burden; thus carer burden and distress are often inextricably linked (Springate and Tremont, 2014).

5.11.3 Quality of Carer Patient Relationship

I wanted to understand the quality of the carer and care recipient relationship and in my sample, most PWD and carers perceived the quality of their relationship similarly.

There are no population based data for this but compared with the study of Spruytte et al. (2002), it appears that the people in this sample regarded their relationships as satisfactory. This is perhaps to be expected as they would require a fair degree of harmony to agree to participate and discuss these sensitive issues. However, I did not measure the historical quality of their relationship before the onset of dementia and therefore cannot ascertain how dementia may have changed the quality of the relationship.

The QCPR is a scale developed specifically to be applicable to all types of carers, based upon the literature of expressed emotion. Thus it was of benefit when applied to my sample as it could include both spouses and adult children. The scale also includes both positive and negative relational aspects whereas some others only focus on the positive, on one particular type of relationship (for example, Van den Broucke et al., 1995). Whilst the scale was easy to use, involving only 14 self-rated items (Appendices 17 and 18), some participants questioned what was meant by certain terms or words, for example, item 7: 'My relative and I are tender towards each other', I would offer the alternative words of 'caring' or 'loving'. Also item 2

presented a problem in that it confused some participants: 'My relative and I often disagree' with the option of 'disagree' being one of the ratings. I had to explain this in greater detail on occasions. This may have exerted a researcher influence on the participants' response to these items; even though I was consistent in the explanation I gave.

5.12 Treatment choices at the end of life

The main instrument I used to assess treatment choices at the end of life was the Life Support Preferences Questionnaire, which was originally designed to support decision making in preparation of advance care planning in the USA (Ditto et al., 2001; 2003). This study is the first to pilot a modified version of the LSPQ in the UK.

The LSPQ was modified in my study using only three of the original nine items as I was piloting its use in dementia and for the purposes of this study. However, the three scenarios used were as in the original tool. A concern that arose for several participants was that, given the brief information on scenarios two (significant stroke and coma) and three (terminal cancer with six months to live), they felt it was insufficient to apply to their own situation and to be able to generate sensible and informed choices.

Vignettes are commonly used in studying sensitive healthcare issues because the obvious ethical problems in asking opinions at the bedside of a dying patient make it a difficult issue to research directly. The vignette method can be used to extrapolate data by asking study participants how they *would* act under certain circumstances (Kodadek and Feeq, 2002; Hughes and Huby, 2002). Researchers often use vignettes to explore end of life decision making and avoid the ethical problems of using real life cases (Denk et al., 1997). Vignettes can generate data quickly and

cheaply (Gould, 1996) and can enable the researcher to tackle potentially difficult topics of enquiry (Barter and Renold, 2000).

In my study, whilst no participants expressed concern or distress in respect of the topics raised in the vignettes of the modified LSPQ, they often found it difficult to make some treatment choices as they felt the vignettes held insufficient information to guide them. This led to a high degree of uncertainty and therefore an inability to make a definitive treatment choice. Whilst vignettes may attempt to mimic healthcare scenarios, they fail to reflect their complexity. The lack of specific detail may lead participants to make ill informed choices that do not reflect reality.

5.12.1 Predicting agreement between PWD and carers

Agreement for end of life treatment choices varied across the three scenarios. Most participants displayed a high level of agreement in the 'here and now' which, is encouraging but perhaps easier to predict as it is the lived, current state. This concurs with findings of other studies in a review by Shalowitz et al. (2006). However, most PWD were in good physical health so treatment decisions were not, or had not, been required, other than perhaps minor ones.

Carers found it relatively easy to anticipate the wishes of the person with dementia in the 'here and now' as it is a *known* situation and requires no hypothesising. However, as the healthcare scenarios became more focused on possible illness states in the future, agreement declined to moderate, at best. Furthermore, treatments that were more interventional, such as CPR and tube feeding, had lower levels of agreement across all scenarios.

Modified LSPQ, Scenario one ('As you are today')

In an earlier stage of this study (Chapter 3), I found that PWD were able to make

their preferences known for the future but these were based very much in the here and now, finding it difficult to conceive of their future self in abstract situations. Unsurprisingly then, PWD felt confident in making treatment choices in scenario one. Almost all elected to receive antibiotics but the number decreased to 50% when considering tube feeding. These findings concur with those of the phase one, nominal group study, (Harrison Denning et al., 2012) in that PWD can perceive of their wishes and preferences in the present but struggle when considering their future self. All PWD had previous experience of antibiotic treatment whereas tube feeding is more invasive and uncomfortable and was less familiar to them.

Modified LSPQ, Scenario two (Severe stroke and coma)

Approximately half of the PWD preferred active treatment in this scenario but with over a third expressing uncertainty (Table 5.8). This is consistent with findings in phase one of this study (Chapter 3; 3.11) and may be due to an inability to conceive of their future selves in conjunction with a minimal description of the illness states of scenarios two and three and their implications. Carers, on the other hand, tended to overpredict a preference for non-active treatment in the PWD. It might be that they found it difficult to divorce their own wishes and preferences from those of the PWD, that is, they may have been considering what it would be to have the condition themselves (see also 3.11).

Modified LSPQ, Scenario three (Advanced cancer)

As in scenario two, PWD found it difficult to think about what they would choose and whilst half wanted active treatment in the form of antibiotics, when it came to other, more invasive treatments this dropped to approximately one third. Carers showed a similar pattern in predicting active or non-active treatment choices of the PWD.

The purpose of my study was not so much to explore people's perceptions of

different treatments but whether they would choose it. However, future study of people's perceptions could provide information for clinicians on how best to present information on such interventions in a balanced way, perhaps involving pictures and diagrams.

5.12.2 Other factors influencing treatment preferences

It was perhaps surprising that other variables relating to the PWD had no statistically significant influence on the concordance between them and their carers. One might have expected that factors such as, age, or occupational history might have influenced people's future choices at end of life. The fact they did not may be due in part, to the relatively small sample size. However, these preferences and choices may be more influenced by a person's spiritual and ethical framework, previous experiences of healthcare and decision making for others; these data were not collected in this study.

Overall, carers were only able to predict the treatment preferences of the person with dementia to a moderate degree. I did find that carers with more evidence of psychological distress as measured on the K(10) were less accurate at predicting the treatment preferences of the PWD. This is consistent with systematic review findings of the negative psychological impact on carers in making treatment decisions for others (Wendler and Rid, 2011). This makes sense as one might expect that all types of decision making would be impaired in the presence of psychological distress.

5.12.3 Uncertainty in treatment choices at end of life

I found that there was a significant amount of uncertainty both in PWD and carers in respect of treatment choices in future scenarios. Carers of PWD had difficulty in

developing a view on the probability of illness outcomes and in their role as proxy decision makers in the absence of emotional support and the provision of relevant information. Schenker et al. (2012) found that carers struggle to reconcile personal emotional needs with those of the person for whom they care, struggling to make decisions based on what they think the PWD would have wanted. Mishel (1988,1990,1991) described a 'theory of uncertainty' whereby, in illness-related situations, the decision maker finds it very stressful and difficult to make a judgement or to predict what an individual might or might not want due to lack of cues and information. Mishel (1988) initially proposed that the 'theory of uncertainty' in illness had its strongest influence in those experiencing an acute phase of illness or downward trajectory. However she reconceptualised this theory in later research, considering uncertainty in the context of prolonged, chronic illness (Mishel, 1990).

In dementia care there is much uncertainty around issues such as the struggle to gain a diagnosis, lack of information about the prognosis of dementia and lack of knowledge about care and treatment options for the future. In the ZBI interview to assess carer burden, item number seven asks - 'Are you afraid what the future holds for your relative?' Interestingly, the majority of carer respondents indicated 'quite frequently' or 'nearly always'. This may be due to several factors. In phase one of this study family carers perceived their future (and that of the PWD) as bleak (see 3.10) even to the point of considering euthanasia should they also develop dementia. There may also be a lack of information on what the future holds for them and the person they care for. However, even those carers who 'know a lot' may still be fearful of the future and the course of dementia.

Perceptions of one's situation within the context of an illness such as dementia may induce a response shift when completing self-report measures in research.

Response shift (RS) refers to the changes in internal standards, values, or in the conceptualisation of illness which are influenced by health state changes (Sprangers and Schwartz 1999; Schwartz 2010). Response shift biases can have an impact on the validity of the questionnaire or survey to which the participant is responding. Potential biases may be considered both for the PWD and the carer. Whilst RS has largely been described in the context of quality of life such an effect may result in biases of carers' responses. They may be influenced in choosing treatments *they* would or wouldn't want for themselves, rather than for the person with dementia. The choices of the PWD may be influenced by the perception that living with dementia is turning out to be not quite as bad as they originally thought, though as cognition declines the ability to recalibrate their response will become less possible. However, as my cross-sectional interviews were a once only recording any response shift from baseline was not measured. As carers and PWD are influenced in different ways in their perception of the situation with dementia, then they may well be led to different perceptions of future outcomes or different choices in relation to future scenarios.

Uncertainty about the future affects not just carers but also professionals (Dickinson et al., 2012) (see chapter two, 2.3.2.1 and 2.4.7). We will need to give more consideration to the issues of uncertainty if we are to reduce the distress and burden for carers in decision making and also to prepare professionals in providing appropriate support. My findings, in respect of the emotional toll and day to day uncertainty surrounding decision making, add further weight to an argument for timely diagnosis (see 1.6.2) and information about the probable course of the illness. A post-diagnostic intervention of care management and navigation, such as Admiral Nursing, may be useful to support carers and PWD to make informed choices about future care and treatment as the illness progresses.

5.13 Strengths and limitations to the study

The main strengths of this study are that it was based on foundations of both clinical enquiry from my experience as a practitioner and also the research described in Chapters 2 and 3 (systematic review and nominal groups). Although recruitment was slow, as discussed below, recruiting 60 dyads in a sensitive area of research gives a sample size comparable to other studies in the field (Ayalon et al., 2012; Hare et al., 1992). Once recruited, nearly all the participants took part enthusiastically and their comments about the limitations of the standard instruments led to the further study to be described in Chapter 6. All the interviews were conducted by a single researcher which adds to the consistency of the research approach but may have introduced systematic researcher bias.

Instruments for exploring preferences for future end of life treatment (LSPQ) and the quality of carer-PWD relationship (QCPR) were carefully chosen and relatively novel in their use, especially in a UK context. So the data gathered are of interest from a methodological perspective as well. However, dichotomising results in these two measures, as utilised by their authors, may have had the effect of reducing the richness of data analysis

Another strength is that in my analysis I reported on the level of uncertainty in making treatment decisions by the PWD as well as the carers in predicting those treatment choices. In some of my analyses 'uncertain' choices were subsumed into 'want treatment' but I undertook separate analysis to clearly distinguish between the categories of 'want', 'don't want' and 'uncertain'. In their review, Shalowitz et al., (2006) criticised studies that had classified 'uncertain' responses from patients and carers as acceptance of the treatment intervention in question, arguing it may have influenced overall results. In my study I analysed the level of uncertainty in respect

of specific treatment options. Where a marked degree of uncertainty exists around some treatment options this can be a clear indicator to target information resources and decisional support in those instances.

Recruitment

Recruitment was slow, taking nearly two years to achieve a sample of 60 dyads. This was despite having access to four geographical areas and two dementia research registers. However, there are several factors to consider. I was recruiting dyads; the person with dementia and their main carer, so requiring the two together may have restricted recruitment rates as there may have been individuals on the research register whose counterpart did not wish to be involved in research. Also as this was a part time doctorate, time spent with clinical teams to support recruitment was restricted. However, other studies that have explored dyadic agreement have samples of similar size, for example 50 dyads (Hare et al., 1992) and 53 dyads (Ayalon et al., 2012), but it should also be noted that these studies had several people available to conduct interviews.

I could have tried other strategies to recruitment, for example peer support groups, Alzheimer cafes, etc. However, while this may have yielded volunteers for the study, it would have added more stages to the recruitment process, because of the need to contact clinical teams to verify diagnosis, suitability, etc. As it was, in my study, some clinicians expressed caution in suggesting some dyads reasoning that they had only recently received the diagnosis and thus possibly it was too soon to seek their interest in a study that focused on ACP and end of life care. This caution may be due to concern borne out of knowledge of the clinical status of the patient but may also reflect a reluctance to discuss the nature of the research topic for fear of causing distress. Attempting to recruit from peer support groups may also have

required screening more potential participants who did not meet the inclusion criteria.

Dementia research registers are increasing in number around the UK and in many cases can make it easier for researchers to access participants, as well as enabling more people affected by dementia to become involved in research. I had contact with two dementia registers, both of which were databases that were independent of the electronic clinical record systems. Time was lost as the clinical and contact details of potential participants in one register were inaccurate or significantly out of date. Keeping personal data held in databases that stand alone from clinical records up to date is challenging. Access to research for people affected by dementia and access to recruits for researchers may be in future be enhanced by the 'Join Dementia Research' initiative¹⁶.

A further barrier to recruiting PWD was a carer's tendency to act as gatekeepers to their participation, either through restricting access or permission in various active or passive ways. Although few dyads declined to take part, some carers acted as spokesperson so I was left unclear as to the wishes of the person with dementia. Karlawish et al. (2000) found that, in dyads, carers had influence over whether they both enrolled for research; other researchers concur (Sugarman et al., 2001; Berger and Majerovitz 2005). Karlawish et al. (2000) report reasons for not enrolling were often focused on hassles and burdens for carers, such as travel and time taken. They concluded that where a carer experiences a high degree of distress and related problems such as depression or loss of control then they are less likely to enrol in research. Thus there may have been a systematic recruitment bias, where more distressed carers declined to take part in my research.

¹⁶ <http://www.crn.nihr.ac.uk/dementia/about-dementia-research/join-dementia-research/>

The sample

In the event, participants were recruited on an opportunistic basis. It is clear from the demographic data presented in Table 5.2 that the sample of participants is unlikely to be representative of the general population of the UK with dementia in terms of social class, educational level and ethnic background. They also probably reported lower levels of carer burden and carer distress than might be found in a general population sample, as well as which they appeared to have generally good mutual relationships as evidenced by the QCPR data. This selection bias is widely encountered in cross-sectional surveys especially if the study sample is essentially a volunteer group; the resources of this study had no means of adjusting for any bias that this may produce. It occurs when those who participate, differ in some way from those who do not, and that this systematically alters the prevalence of the outcome of interest. It is possible therefore that the findings cannot be generalised across the whole population. However, it is striking that even among an articulate and relatively well educated group, with relatively mild levels of cognitive impairment, people still struggled to conceptualise the future and were hazy in their understanding of future medical eventualities. In practice, it would be difficult to obtain a wider and/or more impaired sample as people may simply lack the capacity or willingness to discuss sensitive issues around end of life care.

Methods and analysis

The two main carer instruments used were the Zarit (ZBI) and the Kessler (K10) which measure burden and distress respectively. The ZBI especially has been criticised for focusing on the negative aspects of the carer experience and neglecting positive aspects, such as personal satisfaction, role status, reciprocity and skill acquisition. However, it is in wide use clinically and in research so this influenced the decision to use it. There were no statistically significant associations

with the prediction of treatment preferences of the PWD on the modified LSPQ in relation to carer burden and only limited results for general carer distress. As I did not use a measure of carer satisfaction, I cannot tell if positive aspects may be more important in predicting the health care preferences of PWD. This may be an avenue for future research.

Problems were encountered when using Cohen's Kappa coefficient (Cohen, 1960) to calculate levels of agreement in treatment choices across the modified LSPQ. Extremes in levels of agreement, either very high or very low, limited the application of the Kappa statistic so PABAK was used (see 4.10.3), albeit only with partial resolution of the problem. I would concur with others (Sulsamy et al., 1998), who have expressed scepticism regarding the appropriateness of the Kappa statistic for measuring carers' predictive accuracy. Kappa is said to take into account the agreement occurring by chance by the so-called chance adjustment. I think that in my study, participants took the default option of being 'uncertain' rather than making the choice 'want' or 'do not want' treatment. In the event, data derived simply by developing a prediction index (5.8.13) produced results consistent with those of the Kappa coefficient, that is, carers were only moderately able to predict treatment the choices of the person with dementia. None of the factors tested were associated with the degree of concordance between the PWD's preferences and the carers prediction of those preferences.

Conclusion to this chapter, as for Chapters 2 and 3, will be presented in summarising the thesis in Chapter 7

6.1 Introduction

This chapter discusses the final part of my research. The cross sectional interview presented in Chapter four did not include any qualitative data collection or exploration of personal opinions or dialogue. In practice, during the interview process, dyads often wished to qualify why they responded in certain ways to the questions posed and offered a rationale for their answers. In the original protocol I had made no application to record such information. Realising that this potentially presented some valuable qualitative data, which may deepen my understanding of the quantitative data, I therefore sought a substantial amendment to the original protocol (12/LO/0106) from South East Coast Kent REC to include a brief semi-structured interview schedule. This was approved on 30th October 2013 (Appendix 22).

6.2 Aim

The aim of this phase of the study was to explore the context for healthcare decisions, past, present and in the future of both the person with dementia and their family carer in order to add to the understanding and interpretation of the quantitative data gleaned in the cross sectional data collection.

6.3 Methods

6.3.1 Design

A qualitative approach was taken to this phase as in chapter three (3.7.2), drawing upon a naturalistic interpretive approach (Ritchie and Lewis, 2012; Topping, 2010). Content analysis was used as a qualitative research method for sorting, synthesising and analysing data from the nested interviews (Ritchie and Lewis, 2012). Content analysis is a useful approach to examining data within a given

context and in the triangulation¹⁷ of data collected through mixed research methods (Given, 2008). Robson (2002) argues that this approach allows both the examinations of content and context to enable any research to link the qualitative data to quantitative 'outside variables' such as gender. Creswell and Plano Clark (2011) define mixed-methods by the linking or integration of two forms of data concurrently by combining them or embedding one within the other. For the purposes of this phase of the study content analysis of six, nested qualitative dyad interviews, embedded within the dyad interviews, was undertaken to add the 'lived' context to the data retrieved through the cross sectional data collection.

The qualitative interviews enabled a richer understanding of the context of decision making within the dyads. A brief interview schedule of three qualitative questions (Appendix 23) provided access to the perceptions and opinions of dyads and an insight into the personal aspects of healthcare decisions that were not immediately perceptible or recordable using the original interview schedule (4.8.2.).

As data of this type are suited to working with small samples I aimed at six dyad interviews (Polit & Beck, 2009), principally to supplement and validate information derived from the cross sectional quantitative interviews (4.8.2).

6.4 Study location

For pragmatic purposes, dyads were selected from those that had already been interviewed within one location (BEH Mental Health Trust), to restrict the approvals required to one R&D site.

¹⁷ Triangulation in qualitative research has come to mean a multimethod approach to data collection and data analysis. The basic idea underpinning the concept of triangulation is that the phenomena under study can be understood best when approached with a variety or a combination of research methods (Given, 2008).

6.5 Participants

6.5.1 Inclusion and exclusion criteria

Inclusion and exclusion criteria remained the same as for previous phases of the study, however, specific additional inclusion criteria were:

PWD

- Previously interviewed for phase two of this PhD study in BEH.
- MMSE >20.
- Mental capacity to give consent to participate in the study and take part in the semi-structured interview.

Carer

- Previously interviewed for phase two of this PhD study in BEH.
- Mental capacity to give consent to participate in the study and take part in the semi-structured interview.

6.5.2 Identification of participants

A purposive sampling approach was employed (Polit & Beck, 2009) (see also 3.5.7). Polit & Beck define a purposive sample as one that is selected based on the knowledge of a population and the purpose of the study. Thus, in this part of my study, the dyads were selected for a range of ability of the carer to predict the treatment preferences of the PWD. The index of agreement developed during statistical analysis (5.8.13) was used to select six dyads: two that demonstrated a high level, two a medium level and two low level of agreement. This was to seek the

views and opinions of dyads that reflected, where possible, the range of levels of agreement on the modified LSPQ.

To ensure the dyads thus selected still met the inclusion criteria, I contacted the manager of the Dementia Research Register and clinical staff to seek their views on each dyad's continued suitability before re-approaching them.

6.6 Recruitment

Each potential dyad was contacted and a verbal explanation of this additional element of the original study was given by the researcher; this was followed up with posting a brief information sheet to each dyad that were considering their involvement (Appendix 24). I allowed a minimum of seven days to allow time to read the information and discuss with others, if wished. A second telephone contact was made to seek consent to inclusion in the study. Full opportunity was offered at each point for participants to ask questions or seek clarification of this final stage of the study. The researcher carefully explained any points in the information sheet where clarification was sought.

6.7 Obtaining informed consent

All participants were asked to initial and sign a consent form (Appendix 25 & 26) that was then countersigned by the researcher. Copies were given to each participant, another copy was held in the care records of the person with dementia and one saved in the study documentation file.

6.8 Demographic Data

Demographic details of all participants and the relationship of the PWD to their carer had already been recorded (Table 5.2), but Table 6.2 characterises this subset of participants in terms of age, gender, ethnicity, previous education, living situation and dyad relationship.

6.9 Data Collection

A brief, semi-structured interview schedule was designed (Appendix 23) with key questions (6.9.1). Creswell (2003; 2009) identifies several stages to developing a semi-structured interview, to include (a) the preparation for the interview (see participant information sheet, appendix 24), (b) the constructing effective research questions (Appendix 21), and (c) the actual implementation of the interview(s).

Three open questions were developed allowing respondents' to give full answers to questions with as much explanation as they chose. I then used prompts to ensure the question was answered as fully as possible, and to follow up on any particular responses made by individual participants (Turner, 2010). Thus, once each opening question was posed the interviews were conversational in style to allow me to follow any relevant avenues of enquiry as presented by the participants (Polit and Beck, 2009; Oppenheim, 1992).

6.9.1 Interview questions (brief interview guide, Appendix 23)

Historic patterns of healthcare decision making:

1. How have you made decisions about healthcare and/or treatment wishes in the past?

The effect of a diagnosis of dementia upon healthcare decision making:

2. What changes to this decision making process (if any) do you see the diagnosis of dementia has made?

Future healthcare decision making in the light of the dementia diagnosis:

3. What healthcare and/or treatment decisions may you need to make in the future now that there is a diagnosis of dementia made (for you/your family member)?

All interviews were conducted between December 2013 and January 2014 by KHD and each lasted between 25 and 40 minutes. Interviews were digitally audio recorded to ensure that all aspects of discussions and conversation nuances were captured. In addition, field notes were taken to record observations of nonverbal communication such as worried expressions, raised eyebrows, etc.

Participants were offered a choice of location for the interview, including their own home or an interview room within the memory clinic. All chose to be interviewed at home.

6.10 Data Analysis

Interviews were transcribed verbatim, anonymised, encrypted and stored on the UCL secure H drive. Once transcribed, all audio recordings were deleted from the recording device and stored within NVIVO 8 qualitative analysis software (QSR International, 2008). A content thematic approach was adopted incorporating a

number of stages to systematically organise, reduce, refine and analyse the data (Braun and Clarke, 2006; Ritchie and Lewis, 2012).

Each transcript was read and re-read until a thorough understanding of the content was achieved and commonalities and differences amongst the interviews were identified as patterns, or themes, within the data. Categorisation of the data followed whereby these early themes were formed into descriptive codes and the data were subsequently reduced (Ritchie and Lewis, 2003; Braun and Clarke, 2006).

Many challenges have been made to the rigour and bias potential of qualitative research methods (Bryman & Burgess, 1994; Mason, 2002) as all descriptions involve selection and interpretation of meaning by the researcher. To allow for this potential researcher bias and as a means of increasing the rigor of the analysis (Saks and Allsop, 2007), transcripts were initially coded independently by myself and my supervisor (ELS), before agreeing on the final coding frame. A sample of dyad interviews were independently blind coded and themed by a member of the Marie Curie Palliative Care Research Unit (NK). The analysis continued as themes were defined and redefined ensuring all data were represented (Miles and Huberman, 1994) with any discrepancies and/or differences being discussed with agreement and consensus reached between the independent researchers coding.

6.11 Results

6.11.1 Participant characteristics

Six dyads agreed to participate, with one additional carer, the adult son of one dyad (Dyad D), included in the interview. The average age of the six participants with dementia was 77.6 years (ages ranging from 70 to 88 years). The mean MMSE score was 24.8/30 (range 22-28). The average age of the seven carers was 73.4 years (range 49 to 85). All carers were spouses of the person with dementia, except for the additional adult son in dyad D (Table 6.2.).

Table 6.1 Characteristics of dyads

	PWD (n = 6)	Carers (n = 7)*
Age (mean [range])	77.6 [70-88]	73.4 [49-85]
Gender (male)	3	4
MMSE (mean [range])	24.8 [22-28]	
Diagnosis (ICD 10)		
F00.1 (Alzheimer's late onset)	5	-
F00.2 (atypical or mixed type Alzheimer's)	1	-
Ethnicity		
White British	3	4
White other	3	3
Previous education		
Left school ≤ 14 years	2	1
Left school ≥ 14 years	4	6
Living situation of PWD		
Spouse	6	-
Relationship to PWD		
Spouse	-	6
Adult child	-	1

Note: * = one interview involved an adult child in addition to the spouse. PWD = Person With Dementia. MMSE = Mini Mental State Examination. ICD 10 = International Disease Classification

Table 6.2 Participants level of agreement using modified LSPQ

Dyad ID	LSPQ score (see table 5.23)	Level of agreement
Dyad A	6/9	Medium (M)
Dyad B	9/9	High (H)
Dyad C	8/9	High
Dyad D	2/9	Low (L)
Dyad E	3/9	Low
Dyad F	6/9	Medium

6.11.2. Emergent Themes

Several themes emerged from each of the three questions in this interview schedule. They will be discussed in relation to each of the interview questions (6.9.1):

6.11.3 Historic patterns of healthcare decision making

Untested decision making

The first question posed sought to explore how dyads had made healthcare decisions historically. Some felt that there had been no call to make any major healthcare decisions, until the diagnosis of dementia, so decision making had largely remained untested.

...there were very few major decisions we ever had to make.

(Carer, Dyad C, High agreement)

...well, fortunately there were never any major ones...[only] things like vaccinations...

(Carer, Dyad D, Low agreement)

Shared decision making

However, many proposed that their approach would have been one of shared decision making and spoke of guiding principles that would prevail should they have been required to make such decisions about healthcare.

Well, we discuss it for a start and see what each one would say and then decide to come to a decision...I would never do anything without asking [name] about it or getting his opinion and he would do the same. Yes?

(PWD, Dyad C, High agreement)

Yes, I think we've always discussed something...like...when there were all those scares about eggs or animal fats...

(Carer, Dyad B, High agreement)

...I don't think we would do anything the other didn't want to do...

(Carer, Dyad A, Medium agreement)

...you wouldn't make any decision without discussing it with me..(?).

(PWD, Dyad C, High agreement)

...we talk about...and then we see...we talk...and which one is right and which one is wrong...

(Carer, Dyad E, Low agreement)

Gender specific decisions

Dyads talked of the decision to have children together as perhaps one of the first, or often the only, decisions they had made as a couple. Largely the decision to have children was motivated more by females than males.

...when he asked me to marry him I said I wanted lots of children...I said six but I got five...

(PWD, Dyad A, Medium agreement)

In one instance pressure to have children was felt from the female parents of each couple, with the view that this was culturally driven.

It was both our mothers. They both decided it was about time...they were both good Jewish women...

(Carer, Dyad F, Medium agreement)

Decisions about the number of children also tended to be driven by females. However, in one dyad the male partner decided that he could only emotionally cope with one child. His decision was so overriding that it led to the abortion of a second pregnancy. This was a difficult decision for his wife to accept, but the couple acknowledged that they were only able to take this action because they were very close in their relationship and in their support of each other.

...well, it's something that I regret [having one child]...but I said quite firmly...one is all I can cope with.

(PWD, Dyad B, High agreement)

...I never wanted only one...I did it...because...his emotional state was such that I didn't think he would survive it.

(Carer, Dyad B, High agreement)

There was some evidence that gender continued to play a part in decisions relating to children; the wife making smaller, health related decisions for the children on a day-to-day basis with the husband more likely to become involved in the making of bigger decisions.

...that was my domain...I mean...I made all of those decisions. He was very busy working...

(Carer, Dyad D, Low agreement)

...a spinal tap...[for their son]..lumbar puncture...we had to decide about that...we shared the decision really...

(Carer, Dyad F, Medium agreement)

However, in spousal relationships, the wife tended to have less influence on past decisions. In one instance a wife talked about how she tried to encourage her husband to seek help for symptoms of overt tiredness but was being ignored. She took the matter into her own hands and made the decision to call their GP.

...[constantly fatigued]...I kept telling him to go see the doctor...I rang the doctor without telling him...

(PWD, Dyad C, High agreement)

Whilst this action initiated an angry response from her husband, he was able to gain effective treatment for an underlying condition. However, he was firm in his belief that she should not have made this decision for him.

...she rang the doctor without telling me...we actually had words about it...I was scared...I had a bypass. And um...I would probably have...I didn't ...have a heart attack or anything...

(Carer, Dyad C, High agreement)

Autonomy in decision making

However, there was evidence to show that many were autonomous in decision making. In one instance each partner had attempted to exert health promoting behaviours on each other but the pressure to conform to healthier habits was resisted. One dyad discussed a wife's smoking habit:

...[name] absolutely detested it. We'd try...he'd try to talk to me about it [stopping] and I couldn't talk about it...it's got to come from me...

(Carer, Dyad B, High agreement)

...I just saw it as being the sensible thing to do...

(PWD, Dyad B, High agreement)

Often there was one partner that was more dominant in decision making though this was not always acknowledged within the dyad. One dyad interview was joined by an adult child and a constant theme running through this interview was the spousal carer's dominance in decision making over time.

...well, she is very bossy [regarding decisions]...

(PWD, Dyad D, Low agreement)

...he sees it that way.....I don't see it myself...

(Carer, Dyad D, Low agreement)

Son nods head vigorously

(Adult son, Dyad D, Low agreement)

6.11.4 The effect of a diagnosis of dementia upon healthcare decision making

With the second of the three interview questions, I wanted to explore whether the diagnosis of dementia had made any impact on their usual decision making processes.

Getting the diagnosis

Several talked of the events that led up to the diagnosis of dementia. Some carers talked of how they tried to influence the affected person to seek help. In one instance a son influenced the seeking of diagnosis as the main carer had determined that there was little point in doing so as she felt nothing could be done afterwards. Although the diagnosis was eventually confirmed, the carer then decided that they would tell no one for fear of the stigma associated with dementia. She saw this decision as one that had been agreed by the family though other family members saw this differently.

...we decided we were not going to mention it to anyone outside...only our son, possibly his wife...

(Carer, Dyad D, Low agreement)

...you decided...

(PWD, Dyad D, Low agreement)

Transitions in decision making

Many spoke of dementia being the first time their shared decision making had been tested. Some felt that the diagnosis of dementia marked a transition point with historical, family decision making roles being altered in some way or even reversed.

In one dyad the husband had historically been the main decision maker on behalf of the family but his dementia had now moved this function to his wife.

...well....I have to make all the decisions now really...when it is a difficult decision I ask my girls...[daughters]

(Carer, Dyad E, Low agreement)

Some PWD felt that their decision making abilities were currently unchanged and saw no reason why this would change in the future.

...you don't need to make decisions for me...I can make them...

(PWD, Dyad F, Medium agreement)

...whatever I think...make a decision, they have to...to accept it as well...

(PWD, Dyad E, Medium agreement)

Stepping down

However, some PWD had actively *stepped down* and now deferred all decisions to their partner. Some reflected on how this deferring of decisional responsibility to the carer was a natural evolution rather than a conscious process

I think gradually, particularly over the past six to nine months...I have, um...to some degree, well...pretty well fully...opted out of major decision making....I'm not taking as much responsibility for our lives, as I would have in the past...I know it's an odd way of putting it, but it seems to be the natural thing...as though it's evolved into this state rather than specifically...

(PWD, Dyad B, High agreement)

For most, an incident or series of incidents had occurred that then tested the *new order* of decision making, with varying levels of acceptance. Several carers

demonstrated a wish to 'soften' the reality of the decision making transition in a variety of ways. For some, it was the decisions *not* to do something that were particularly contentious as they worried that it would challenge or upset the person with dementia too much. For example, some carers had made the decision not to go on holiday again as it was felt the effects of the change of environment created more difficulties than benefits.

...I have to decide...ohhh...well...holidays. Holidays are a thing of the past now. We can't go on holidays...he doesn't accept we cannot go on holidays...I say to him how difficult it is to travel with our situation, you know?

(Carer, Dyad E, Low agreement)

We've had to disband holidays for a start because...over the last years now...

(Carer, Dyad C, High agreement)

Compromises

Carers talked of being faced with the responsibility to make decisions to withdraw from or stop doing things as a couple to accommodate the changing pattern of living due to dementia. This often meant the carer made compromises to their social lives, for example, in no longer going on holidays. For one couple this meant that the carer may never see her elderly relatives overseas ever again.

*...I made **that** decision...[does not even mention the word holiday to avoid distress] ...to avoid **that** situation because he gets upset... you know...*

(Carer, Dyad E, Low agreement)

Costs to decision making

The transition to becoming the main decision maker for some carers was felt to be wearisome. Whilst some demonstrated a level of compassion and self-sacrifice in

making 'protective' decisions to 'soften the reality' for the person with dementia, it often came at a cost.

It is probably the practical...everyday decisions...day to day decisions that I have to make...it is very wearing for me...it is very stressful for me...I have my own health problems...

(Carer, Dyad F, Medium agreement)

[the burden of decision making]...to me...most of it...all of it really...

(Carer, Dyad E, Low agreement)

A significant outcome of this transition in decision making was a drive to 'protect' the person with dementia. This was accompanied by a fear of what the future might hold, sometimes mentioned by some PWD but this was largely an issue for the carers. Some were concerned that, should something happen to them, what would happen to the person with dementia?

I dunno...I mean...if he can't decide now...it will be worse in the future, won't it?...while I am carer...then I make the decisions but if I come to a position where he [PWD] is now and I can't make decisions...

(Carer, Dyad E, Low agreement)

6.11.5 Future healthcare decision making in light of the dementia diagnosis

The final interview question sought to explore what healthcare and/or treatment decisions participants may need to make in the future.

Future care

There were certain decisions that carers felt may be required of them at some point but were unsure as to when or how these might arise or how to approach them.

The issue of where care was to be delivered if they became unwell or unable to care arose in several interviews. Some carers felt that admission of the person with dementia into a care home may be a decision that would present itself in a crisis rather than something to plan or avoid:

...I'm 86...I'm quite liable to fall and hurt myself or have a stroke or a heart attack. If that happened it would change the entire set up. The only option would be for [name PWD] to go into a home...

(Carer, Dyad C, High agreement)

I really don't know...I hate to think...erm...about nursing homes, you know, residential homes and that, but if it has to come to that, and there is no other option...then we have to...to decide, there and then, but at the moment I just block it out of my head, I don't want to think about it because...you know...yes...it's hard...

(Carer, Dyad E, Low agreement)

This, perhaps inevitably, resulted in a strong reaction from the person with dementia who, whilst recognising their failing powers as a result of dementia, could not conceive of a time when this decision would ever be appropriate or desired.

[dementia] *...it's not going to get worse...here I am, here I am going to stay...*[tapping finger on table]

(PWD, Dyad E, Low agreement)

Oh God, no...no, no, no...I don't think our boys would allow that anyway...[admission to a care home]

(PWD, Dyad C, High agreement)

Alternatives to a care home admission as a possible solution to future needs did not generally occur to dyads, though several felt that changes as a result of the condition may well require consideration at some point.

Well, it seems to me that there is going to come a time when...there will come a time when I am not aware of it...I mean it's something I've wondered about...

(PWD, Dyad B, High agreement)

Some PWD felt the diagnosis of dementia had changed how they viewed their end of life. One participant had expected her husband to be the one to die first but now acknowledged that her life would be shorter than she had anticipated because of her condition:

Well...he is seven years older than me...I have always thought he would die before me...but it doesn't look as if going to be like that...

(PWD, Dyad A, Medium agreement)

Planning ahead for end of life

There were divided views on whether to plan ahead and if so, how. Several participants held inaccurate beliefs about the legal system to support decision making when capacity was lost, including advance care planning, Lasting Powers of Attorney, and in some cases the status of wills and testaments.

Mum doesn't want to do it... [LPA]...

(Adult son, Dyad D, Low agreement)

[LPAs]...I didn't say not at all....I wouldn't do it until much later on I think...I see it as something you hand over when its necessary, not before...

(Carer, Dyad D, Low agreement)

As well as lacking accurate information on these processes there were mixed views on their effectiveness and when was the most appropriate time to consider or develop these. Many also lacked any information on the legal aspects beyond the name of the respective document and had no knowledge about how to commence the process, whom to involve and what would happen thereafter. However, some were considering making plans for the future and indicated where they were in this:

...we've thought about it, I've got all the paperwork...but you've got to get all...no...because I have got to talk to the kids before I can do it...

(Carer, Dyad A, Medium agreement)

Even if they were aware of the legal processes the dyads seemed to have limited knowledge about the course of dementia and its prognosis and what effect this could have on decision making. Some family members felt that it was hard work to support and influence decision making for the person with dementia:

*...there are certain milestones...that people [with dementia] are going to go through...I am not sure we fully understand what you need to do...I think that with dementia it is more difficult to plan and understand the progression...you don't **really** know what is going on...*

(Adult son, Dyad D, Low agreement)

The burden of decision making

One clear message that came through was that decision making and living with dementia was often difficult and meant only a 'day-to-day' or 'day-by-day' approach

was possible with the bigger decisions seen as too far ahead to be able to emotionally consider or practically tackle.

...day-to-day decisions that I have to make...it is very wearing...

(Carer, Dyad F, Medium agreement)

I can't make decisions...well, I can make decisions...but erm, really, I have to take each day as it comes...

(Carer, Dyad E, Low agreement)

Trust in others to make decisions

Several participants also expressed trust in others when it came to decisions, whether that was other family members, the doctor or God.

...well, it's because I trust her fully...by and large I trust what [name] does...

(PWD, Dyad B, High agreement)

If I can ask the doctors decisions, I mean...we don't know...but if they tell us that it's 95% or 80%...we will, er, have a go...

(Carer, Dyad E, Low agreement)

...that's God's will...I've got good faith...I always trust in prayer...

(PWD, Dyad C, High agreement)

When speaking of trust in professional decision making at end of life several participants spoke of the recent concerns of the Liverpool Care Pathway (LCP). In one dyad the views on the LCP were expressed at length.

...there are several things wrong with the Liverpool...you know...that you are getting nurses making decisions, junior doctors making decisions without full consultation with relations and the senior...physicians...

(Carer, Dyad D, Low agreement)

...in the light of all the...er...misguidance...erm...on balance I was still against the Liverpool Care Pathway unless there was much more control...

(PWD, Dyad D, Low agreement)

The carer had the final say on the LCP issue by stating a concern that external factors may override the wishes of the dying person.

Also there may be other considerations in the professional's mind like number of beds, or meeting targets, erm...those things are around though unspoken...so...

(Carer, Dyad D, Low agreement)

Experience of a death of a close family member often influenced participants' understanding of issues around end of life care, though interestingly, none had used this experience to consider their own situations.

Well, I looked after my sister...I took charge of her [LPA] ...I was her next of kin...anyway, I did it.

(PWD, Dyad C, High agreement)

[talking of a sister] ...she didn't want to talk about it so we didn't..it is such a distressing thing...she was in a clinic...so I didn't feel I had to make any decisions...

(Carer, Dyad D, Low agreement)

6.12 Discussion

6.12.1 Summary of findings

- Decision making in relation to healthcare had largely been untested until the diagnosis of dementia.
- Dyads believed they had an approach of shared decision making though where there was a moderate to low level of agreement in treatment choices in dyads one partner often displayed dominance.
- Day-to-day decision making is burdensome for carers.
- There was a mistrust of end of life care processes, such as the Liverpool Care Pathway.
- Dyads with medium to low levels of agreement in treatment choices found it harder to adjust to the transitions in decision making brought about by the diagnosis of dementia.

Most participants had had little or no experience of major healthcare decision making until the diagnosis of dementia, so as such this had remained largely untested. A larger study considering historic patterns of healthcare decision making would be of interest in testing interventions to develop resilience in a couple's ability to make decisions in the event of later ill health. However, dyads from all levels of agreement on the modified LSPQ (high, medium and low) held the belief that when decisions arose in future the principles of shared decision making would prevail. This view was apparently contradicted by evidence to suggest that, in practice, there was often one who was more dominant in decision making than another. A tendency for one member to exert more dominance in decision making was more evident in dyads with a medium to low level of agreement on the modified LSPQ.

Further, the diagnosis of dementia had a marked impact on the decision making processes within the dyad: there was often a shift to the carer being required to make many more decisions on behalf of the PWD than would have historically been the case. Such a shift of decisional responsibility to the historically less dominant partner could add further burden to them in their new caring role. Many decisions, especially the mundane day-to-day ones were unrelenting and burdensome to carers.

Many participants had had little or no experience of making “healthcare” decisions in the past. What little experience they had was often in respect of whether to have children and if so how many. Although one might debate whether this was a healthcare or family decision, it nevertheless shed light on how important decisions were negotiated. There were also other decisions to make in relation to their children, such as whether or not to immunise them and, in one case, about invasive investigations during a child’s ill health. In the main, women influenced decisions about having a family, family size and simple day-to-day decisions in respect of the children’s health. Most participants had not yet experienced themselves any significant ill health which had tested their decision making as a couple. During periods of ill health to date, most participants had made decisions for investigation and treatment independently whilst acknowledging the support of their spouse and family.

Participants often spoke of the trust they had in others if they had had to make any significant healthcare decisions in the past. Some spoke of the trust they had in their spouse or other family members, feeling that they knew them well enough to be of good support if decisions were required. This was perceived more so in those two dyads that had demonstrated a high level of agreement on the modified LSPQ. In the published literature several authors argue that knowing the person with

dementia will enable a carer (and others) to understand their values and individual decision making patterns (Clarke et al., 2003; Bruce and Schweitzer, 2008). Indeed, most of dementia care is rooted in the principle of *knowing* the person with dementia as being the basis for good person centred care (Kitwood, 1997). Yet I found that the wishes and preferences for treatment and care of many PWD are not understood even by those people who arguably *know* them well. Whilst the argument for autonomy in decision making wherever possible is made for PWD, in reality decisions are often made within a family or relationship context (O'Connor and Purves, 2009). Smebye et al. (2012) found that various family bonds, whether positive or negative, influenced decision making and also affected changes that occurred in roles and power dynamics as a result of the dementia. In my study, I found that some dyads, although they believed they knew each other well, in reality had not had this knowledge put to the test in any important healthcare decisions.

Many also spoke of their trust in doctors, indicating they would expect them not only to guide them but also decide for them as they were the expert. One participant felt that her religious beliefs would guide any decision making and that she was in the 'hands of God'. It could be that many people of this generation are more familiar with deferring responsibility for decision making in a sense of reverential respect, especially to doctors.

Many participants perceived a change in decision making occurring soon after the diagnosis was made. As found in other studies (Smebye et al., 2012), some PWD recognised this transition; letting others take over the decision making was not only acceptable but seen as a natural process. For others, this was less well recognised; they took the view that there was no need to change the current status and that the future would not be any different from the here and now. This is consistent with findings in Chapter three (3.10.1) where PWD also talked of their

lives very much in the 'here and now', unable to think about their *future self*. However, most carers recognised they were increasingly faced with having to assume responsibility for the decisions and welfare of the PWD.

Making decisions came with an 'emotional price tag' for carers, meaning that they could only cope by facing decisions on a day-to-day basis. Feinberg and Whitlach (2002) also identified that carers were most concerned about 'getting through each day' and this influenced how much weight they gave to considering issues lying ahead in the future. Some studies have described various core and problematic areas of decision making: access to services, care homes, legal and financial issues, making plans in the event they were not able to continue caring (Livingston et al., 2010) and treatment decisions (Livingston et al., 2010; Wendler and Rid, 2011). In my study, carers expressed how wearisome it was to be simultaneously considering the wishes of the PWD and being responsible for a variety of daily decisions of varying importance. Many seemed to manage this approach reasonably well but had already made their own wishes secondary to those of the PWD, which added to their perceptions of burden. Those dyads that had demonstrated a medium to low level of agreement on the modified LSPQ found it harder to adjust to the transition in decision making brought about by the diagnosis of dementia, which seems to validate the categorisation of agreement. The carers in these dyads found the increasing call upon them to make the day-to-day decisions more burdensome. This finding is consistent with those of Samsi and Manthorpe (2013), who found that the transition of decision making for PWD can bring with it many added stresses for carers, even in making simple everyday choices on behalf of the PWD. Carers made every effort to ensure the PWD was 'protected' through facilitating day-to-day decisions in such a way as to preserve their dignity but by doing this they often neglected their own needs.

Finally, uncertainty prevailed when asking dyads what decisions they may need to consider in the future. To be able to plan ahead requires the availability of appropriate information to be able weigh up the pros and cons of various options. However, carers expressed need for information on the possible life course of dementia and its impact upon the individual and the wider family. Many dyads did not feel that they had sufficient information with which to consider their future, although studies have shown that such information given in managed chunks can greatly support carer decision making (Wald et al., 2003; Robinson et al., 2013; Livingston et al., 2010). Whilst all dyads found it difficult to conceive of what the future now held for them, or perhaps were in a state of denial, those dyads that had a medium to low level of agreement on the modified LSPQ, tended to live for the present day and found it more difficult to consider the application of the various options for planning ahead, such as LPAs.

Some participants had experience of life limiting conditions and death in other family members, which included both providing care and being appointed as decision makers within LPAs. They reflected on what this process involved and the healthcare decisions their relatives had made that in time they had supported. However, this had seemingly not influenced how they perceived their own situation or how such processes could be applied to themselves. Nor did it seem to have influenced them to make LPAs or advance care plans for their own future. This is in contradiction with findings of an observational cohort study of older people by Ajmad et al. (2014). Amjad and colleagues concluded that older people who have experience with end-of-life care of others demonstrate greater readiness to participate in ACP. However, many participants spoke of their concern and mistrust of 'care plans' that were used in healthcare to manage end of life care and made specific reference to the Liverpool Care Pathway (LCP). Several were aware of the media reports on the LCP and one family had medical friends who were involved in

focused debates on end of life pathways. Their mistrust was based on the potential for the LCP to be poorly managed and on concerns about junior staff making important decisions without experience or skills to do so. This again concurs with concerns raised in Phase one of this study (3.10.1) where carers described it as ‘a slow count to death’.

6.13 Strengths and limitations

Recruitment to this small qualitative study was effected very quickly, following ethical approval, as the sample was drawn from previous interviewees of the cross sectional study (Chapter 4). Such purposive sampling is likely to have a recruitment bias as the participants already knew me and a relationship had been established so they perhaps agreed more readily because of this. However, an established relationship may have given the participants greater confidence and comfort in discussing very complex and personal issues.

For pragmatic purposes of travel and access only participants from BEH were approached for this part of the research. This potentially introduced bias as the sample was not necessarily generalisable to a whole population. Data samples of two dyad interviews were coded and themed independently of KHD and ELS to ensure rigour and validity, which was a strength in the data analysis.

Whilst it is acknowledged that saturation of data in qualitative interviews can be achieved with small numbers, a larger sample may have afforded more confidence in the robustness of the findings and make them less dependent on a very small number of people and achieve greater anonymity within the data for participants. However, because the focus of the nested interviews was to focus on the social context of decision making, it identified the perspectives of participants. Though it

may be argued that such qualitative data is not generalisable, it does place some emphasis the unique experiences of the selected participants through the interpretation of the researcher. Further, conducting research from an interpretive paradigm allows the research to be more flexible and allowing other factors to be considered. Saks and Allsop (2007) argue that such an approach, though at the cost of attempting to generalise, allows us to investigate aspects that do not fit our presuppositions about a particular phenomenon.

In this part of the research I categorised the levels of agreement within dyads into high, medium and low. This seemed to be supported in that there were observable differences between dyads in the different categories. However, the subsamples in each category are very small in number ($n = 2$) so a larger sample would have been helpful to explore these differences. Also there could have been some unconscious circularity in coding actively for differences between the three groups.

A limitation of this small qualitative study is that all of the participants were white, however, half of the sample declared themselves as being white other, and this did include a mix of ethnicities: Irish, Greek Cypriot and Jewish.

6.14 Clinical Implications

Post diagnostic support and counselling needs to take into account the changes that occur in decision making patterns within family relationships. Clinicians, when considering how they may support families in building their resilience in living with dementia, need to understand previous relationship strengths and weaknesses as this may either indicate qualities on which to maximise or indeed may highlight areas for increased support or intervention.

Carers may require specific interventions to support day-to-day decision making that maximises the strengths of the PWD for as long as possible. This will need to factor in a PWD's wish to retain a sense of control and dignity while at the same time balancing carers' needs as the relationship changes because of dementia.

In supporting advance care planning for the person with dementia clinicians will need to explore the couple's approach to and ability to make decisions (Boyle, 2013); this should consider any carer tendencies to dominate or assume that they know best.

Families affected by dementia require support from the point of diagnosis in order to plan for the future. This needs to take into account past experiences of decision making, past experiences of illness in themselves and other family members (Amjad et al., 2014), the prognosis of dementia and end of life care and death. This support is best delivered in an ongoing professional relationship rather than as a 'one off' session (Harrison Dening and Wharrad, 2010; Harrison Dening, 2011).

The conclusion to this chapter, as for Chapters 2, 3 and 5, will be discussed collectively in Chapter 7.

7.1 Summary of findings from all sections of this research

To remind the reader, I summarise and draw together the key findings of all parts of the study:

Chapter One – Background (1.10)

- Dementia is a progressive, irreversible neurodegenerative condition that greatly reduces life expectancy, with one in three of the population likely to die with or from dementia (see 1.5.6 and 1.10).
- Department of Health policy (DH 2008) states that everyone should develop an advance care plan (ACP), including the person with dementia (PWD), to prepare their end of life care preferences (see 1.6.2 and 1.9).
- As dementia progresses, family carers find themselves increasingly called upon to make end of life care decisions on behalf of the PWD, it being assumed that they know their wishes and preferences (see 1.8.5 and 1.8.6).

Chapter Two – Systematic review (2.5)

- There is a limited evidence base for ACP in dementia, how common advance care plans are, their feasibility and benefits for end of life care outcomes (2.5.12).
- The prevalence of ACPs is higher among people from white populations and with higher educational levels (2.4.5).
- People with lower MMSE scores tend to opt more for life sustaining treatments (2.4.3 and 2.4.7).
- Family carers require information and support to make effective decisions on behalf of a person with dementia (2.4.9).

- More evidence is needed to understand the feasibility and acceptability of advance care planning in dementia and whether family carers can accurately predict the choices PWD would make for themselves (2.5).

Chapter Three – Nominal groups (3.11)

- PWD had difficulty conceiving their future selves and therefore found it challenging to consider their preferences and wishes for end of life care (3.10.1 and 3.10.2).
- Carers' own preferences for end of life care were shaped by their negative perceptions and experiences of dementia (3.10.2; 3.10.3 and 3.11).
- When interviewed together with the PWD, carers tended to override the PWD's views (3.10.2).
- There was a mistrust of medical decision making and end of life care pathways, such as the Liverpool Care Pathway (3.10.2). The mistrust was centred on the potential misuse of such pathways by those with less experience, such as junior doctors, which might mean that people die before their time. This also emerged in the qualitative interviews in Chapter 6 (6.11.5).
- The wishes and preferences of PWD need to be 'heard' (3.11).

Chapters Four and Five - Cross sectional interviews (5.11)

- In the here-and-now most PWD wanted active treatment. Carers predictions for this were similar in all but tube feeding where there was only 50% accuracy.
- In severe stroke and coma the preference for active treatment in PWD dropped to 50%, however, carers tended to over predict the wish for active treatment.

- In scenario three, advanced cancer, PWDs' preference for active treatment of CPR and tube feeding dropped to one third; carer predictions for active treatment were similar.
- Most carers experienced moderate degrees of burden (5.4.1); however, there was no evidence to suggest that burden affected their ability to predict future treatment choices of the PWD (5.8 and 5.9).
- Carer burden and the quality of relationship to the PWD had no influence on carers' accuracy in predicting treatment choices.
- Almost a third of participants (both PWD and carers) showed a high level of decisional uncertainty when faced with treatment choices for future care (5.5.4 and 5.12.3).
- Carers over estimated the PWD's preference for active treatment in severe stroke and coma (5.4.5).
- Carers were able to predict the treatment preferences of the PWD in the 'here and now' with a good degree of accuracy (5.5.1).
- The ability of carers to predict the treatment preferences of the PWD in future scenarios was moderate to low (2.4.3; 5.5 and 5.6).
- Carers showed moderate levels of agreement with the PWD in the choice of tube feeding across future scenarios; however, there was low agreement for tube feeding in the here-and-now (5.5).
- There was a high level of uncertainty for PWD and carer in making treatment preferences for future scenarios, particularly for CPR and tube feeding (5.5.4 and 5.12.3).
- Carers with higher levels of psychological distress tended to disagree with the treatment preference of the PWD for antibiotics in the here-and-now and severe stroke and coma scenarios (Table 3, Appendix 21).

Chapter Six –Qualitative interviews (6.12)

- PWD and their carers had often had little need to make decisions about health care prior to the diagnosis of dementia (6.11.3).
- Dyads generally believed they had established a shared approach to decision making even in cases where there was a moderate to low level of agreement in treatment choices (6.11.3).
- In dyads where there was moderate to low agreement in treatment choices, one partner had historically displayed dominance in decision making. The historically dominant decision maker in these dyads was not always the carer (6.11.3).
- Day to day decision making on behalf of the PWD increases for carers over time, which becomes increasingly burdensome for them (2.4.11; 6.11.4 and 6.11.5).
- Dyads found it hard to adjust to the changes in decision making brought about by the diagnosis of dementia, especially those dyads with medium to low levels of agreement (6.11.4).

7.2 Final discussion

In this final chapter I bring together findings from all sections of my study and present a final discussion and conclusion.

End of life health policy in the UK states that all people should engage in ACP to guide their future care and in order to inform others if capacity is lost (DH, 2008). However, despite this most people in the UK still do not have an ACP. As discussed (Chapter 1), ACP is a complex process that includes many ethical, legal and values based concepts that would require a degree of imagination, thought and judgement to complete. This doctoral study set out to explore the implications for PWD in

considering treatment preferences for end of life care and a carer's ability to predict them.

7.2.1 Early diagnosis, mental capacity and ACP

I found that PWD, even in the early stages of the illness, find it difficult to consider their future self and think about possible treatment options in the event of future ill health. Previous research in this field has sought to determine the characteristics of a PWD that would indicate ability to engage in ACP (Fazel et al. 1999; 2000, Gregory et al. 2007), but the findings are insufficiently consistent to guide practice. Diagnosis rates have increased since the launch of the National Dementia Strategy (DH, 2009) and diagnosis is usually made earlier in the disease trajectory (Mukadam et al., 2014) but there are still instances where a diagnosis is made later in the course of the disease. Some authors propose that there is a *window of opportunity* where an early diagnosis would enable PWD to engage in advance planning (Fazel et al. 1999; 2000, Gregory et al. 2007; Hertogh, 2009; NCP, 2012), whereas people gaining a diagnosis later in the illness may already have lost the capacity to engage in the ACP process. However, whilst recent studies have demonstrated willingness of PWD to engage in ACP (Poppe et al. 2013; Goodman et al. 2013), I found that even those who were early in the disease process already had difficulty in thinking about their future selves. This means that however early a diagnosis of dementia is made it may already be too late for many people to engage meaningfully in ACP.

7.2.2 Research question 1: Agreement between PWD and carers

My first research question was to explore whether PWD and their family carers agree on preferences regarding life sustaining medical treatments at the end of life. Carers increasingly find themselves being called upon to make treatment decisions

for the PWD as the affected person loses decision making capacity. Clinicians often assume that the carer knows the PWD well and that this familiarity means they will be accurate in their prediction of the person's wishes. However, I found that whilst carers' agreement on treatment choices in the 'here and now' were generally good, in contrast, most carers showed only moderate agreement in choices that the PWD wanted in future ill-health scenarios. This finding, in part, has been found by Sampson et al. (2011) and Hirschman et al. (2008) who highlighted the complexity of end of life care decisions at times of crises and how carers struggle to understand the perspectives of the PWD. Low levels of agreement in treatment choices have been found in studies involving people with long term conditions (Ahluwalia et al. 2011) and such lack of agreement may impair the ACP process (Retrum et al. 2013).

In my study, I found no statistically significant associations between a carer's relationship to the PWD and agreement in treatment choices. However, Ayalon et al. (2012) found that spouses who failed to accurately predict the wishes of the PWD were more likely to ask for treatment. I found that, irrespective of the relationship, carers who were experiencing higher levels of psychological distress were more likely to disagree with some treatment preferences of the PWD; particularly antibiotic treatment in the here-and-now and in severe stroke. Psychological distress in carers increases as end of life approaches for the person they care for (Costa-Requena et al. 2014). Carer distress and depression are predictors of carers having a sense of burden (Springate and Tremont, 2014) though, as these factors are inextricably linked, it may be difficult to determine the direction of causation.

The very function of an ACP is to articulate preferences for end of life care to enable these to be known when capacity is lost and to support carer decision making when

they find themselves called upon to inform decisions in clinical or care situations. As found in other studies (Forbes et al., 2000; Dickinson et al., 2013; Poppe et al., 2013), information about the prognosis of dementia and about potential situations that may arise in the course of the disease are the foundation for shaping preferences for end of life care. As discussed earlier, Amjad et al. (2014) found that past experience of illness and end of life care in others afforded greater insight into what to expect and to plan ahead accordingly. However, in the semi structured interviews, I found that whilst several participants had supported relatives through life limiting conditions and administrated their LPAs, they were not relating such experiences to their own circumstances. Despite active memory clinics and increasing diagnosis rates (DH, 2013b), I found that PWD and carers still have a limited understanding of what the future holds in respect of prognosis in dementia, potential physical health care problems and end of life or death issues.

Perhaps inevitably, families remain beset by uncertainty. It is difficult for clinicians to impart information on prognosis of dementia as each person will experience the illness differently. Many people will never experience advanced dementia as they may die from a co-morbid condition, such as cancer, before their dementia progresses. So giving general information may not be helpful or indeed, may generate unnecessary anxiety and uncertainty. This may further hinder the prospect of engaging in ACP and be significant challenge to clinical services. As discussed earlier in this thesis, Dickinson et al. (2013) found that clinicians found it difficult to appreciate when the best time was to engage in ACP, in what form the discussion should be and who was to initiate it.

I found considerable uncertainty about treatment options at end of life in both PWD and carers. PWD and carers do not know what they should consider in respect of health related decisions for ACP. I found that dyads (couples) also had limited past

experiences of decision making in respect of major health related concerns. Most dyads believe they would share such decision making processes if called upon to do so. However, in those dyads with a medium to low level of agreement on the modified LSPQ, there was often one partner that had historically, been more dominant in decision making in the relationship and this could have been either the PWD or carer. Prognosis and related information requires sensitive and timely delivery (Amjad et al. 2014), but more crucial to this is that it should be imparted as part of ongoing emotional support.

7.2.3 Research Question 2: Factors affecting carers' ability to predict end of life preferences

The second research question sought to explore if good care-giving relationships and lower levels of perceived carer burden and distress improved agreement and a carer's ability to predict preferences regarding life sustaining medical treatments at the end of life. However, I found no significant associations between levels of carer burden and distress and their ability to predict the preferences of the PWD for interventions at the end of life. Whilst dyads rated the quality of their relationship highly, relationship quality, good or otherwise, was not significantly associated with accuracy of prediction.

I did find, however, that carers experience increasing burden from a growing pressure to take on the many small day-to-day decisions on behalf of the PWD. They often find this wearisome; the preoccupation with day-to-day decisions may distract them in their ability to consider those of a more medium and long term nature, such as financial and legal preparations in anticipation of the PWD's loss of decisional capacity. Such eventualities may seem too far ahead or too burdensome for them to think about. This, in conjunction with negative media coverage about

end of life care and treatment guidelines, such as the Liverpool Care Pathway and advance care plans, often makes carers sceptical about the validity of such processes in enabling good end of life care and a timely death.

Carers also find it difficult not only to balance their own needs against those of the PWD but, as I found in the nominal groups (Chapter 3), also project their own wishes and preferences onto the PWD or override such preferences as are expressed by the PWD. At times of crises, this could mean that the wishes and preferences of the PWD are overlooked and the decisions that are made may more closely reflect those of what the carer would want for themselves in a given situation. Services and clinicians must ensure that they approach each case individually with clear information, guidance and support to enable PWD and their carers to think about their wishes and preferences for end of life. This may involve discussions with each party separately as part of an overall advance care planning approach.

If we are to be sure that the wishes and preferences of the PWD are to be respected when capacity is lost, then we need to be confident that these are ascertained if possible when the person still has capacity and that, when it comes to the point of decision in the future, they are applied as accurately as possible. We have seen that carers often find increasing responsibility for decision making can be long and tiring so they do in fact require emotional and decision making support consistently throughout the course of dementia. A clinical approach that has the emotional support of carers at its core, such as Admiral Nursing (section 1.3), may support them in confronting the challenges they face in their increasing role as decision makers on behalf of the PWD.

7.3 Future directions

This study has contributed to research into the field of advance care planning in dementia, exploring if PWD and their carers can articulate their preferences for end of life care. It has also considered how accurate carers can be in predicting such preferences, as often PWD have not developed their advance care plans to guide families. Such findings have implications both for future research and in supporting advance care planning for PWD and their carers in practice. The work is most directly applicable to the UK but also has relevance to decision making and capacity issues elsewhere. The main implications will now be explored.

7.3.1 Implications for research

As the systematic review showed, there have been few longitudinal studies to implement ACP or that measure effectiveness or impact in dementia. One RCT using ACP as an intervention in older people (Detering et al., 2010) found improved patient and family satisfaction and a reduction in stress, anxiety, and depression in surviving relatives. An RCT to consider the efficacy of ACPs on the quality of end of life in patients with COPD is planned (Houben et al., 2014), but I have found none that have focused their attention on PWD and their carers. A longitudinal study that compared outcomes at end of life with those that developed an ACP and those that chose not to plan ahead would give the best evidence of efficacy in meeting peoples' preferences and for cost effectiveness in respect of service use and reducing the use of inappropriate and aggressive interventions.

A study of this kind may, however, be difficult to conduct in practice. First of all, it would require recruitment of an adequate sample size. Second, there may be some challenges in finding participants with capacity to give proper informed consent. Third, the outcomes to be measured at end of life are likely to occur several years

after recruitment and this will create problems in practical management of the trial and the likelihood of obtaining funding. One possible solution is to use an existing population based cohort e.g. the MRC Cognitive Function and Ageing Study (MRC CFAS¹⁸) and follow people who have and don't have ACPs or LPAs longitudinally.

During the course of my study some of the participants in phase one (nominal groups) of this study were also re-interviewed in the second phase (cross sectional interviews). I was struck by the change in views of some PWD. Whilst retaining capacity and insight into their diagnosis of dementia, they had apparently re-calibrated their initial negative views and were enjoying a quality of life that they perhaps thought a diagnosis of dementia would preclude. I explored this phenomenon further and was led to the theory of response shift (RS) (5.12.2). However, in contrast, carers perceived a worsening state of affairs and an increasing sense of uncertainty in light of the diagnosis of dementia.

RS refers to a person's perceived quality of life in the context of illness and a re-calibration to their new health state (Schwartz, 2010). RS was originally meant to apply to subjects rehabilitated from static (non-progressive) pathologies, such as brain injury, to alert the researcher to individual perceptions that may bias data. However, it has been suggested that it may have application in progressive conditions such as dementia (Lawrence et al., 2011).

RS corrects for the fact that the original functional baselines (those we all have in regards to the extent of our motor and mental capabilities) are no longer valid because sufferers of a disease resign themselves (re-calibrate) to using more lenient baselines (Schwartz and Sprangers, 1999). In practice, this means that the original baselines can no longer be compared with current self-assessments

¹⁸ <http://www.cfas.ac.uk/>

(because each measures something else). Furthermore, the re-calibrations can also involve individual definitions of what it means *to be alright*, etc., and also the abandonment or surrender of certain functions and the selection of entirely new functions or capacities to define quality of life.

There is little evidence for RS being either 'deep' or primarily 'cognitive' and it may be that the response shifts seen in early dementia are primarily emotional. RS theory might be of use in clarifying the optimum time emotionally to support the PWD in developing ACPs. Understanding these re-calibrations and working with them alongside PWD and carers may improve their perceptions of the effectiveness of interventions, as has been shown in other areas (Dempster et al., 2010). This may have several potential outcomes that can help us to understand if a PWD recalibrates post diagnostically and if such shifts provide us with evidence of an optimum time at which they may make best use of an ACP intervention.

7.3.2 Implications for policy

There are key points in respect of the implications for end of life health and social care policy.

Living Well with Dementia: A National Dementia Strategy (2009) made minimal reference to end of life care for PWD. One of its proposed objectives was that end of life care for PWD be improved and that PWD should be involved in planning for end of life. It linked with the aims of the End of Life Care Strategy (2008) that indicated that all people should be offered the opportunity to consider their wishes and preferences for end of life in the form of ACP. However, whilst my study did not record how many PWD had advance care plans, they showed limited knowledge of processes that supported any form of future planning, whether or not that is in the

form of ACP. The End of Life Care Strategy also proposed that all people should benefit from coordinated care at a single point of entry, that carers receive practical and emotional support before as well as after the death of the person they care for.

All of this describes a framework within which ACP would be supported. However, as my study has shown, this is not straightforward for PWD and their families. When a diagnosis of a life limiting condition is made, such as terminal cancer, most people will have the opportunity as the condition progresses to consider their future care and be supported by professionals, such as Macmillan Nurses, to do so. PWD and their carers will require similarly skilled facilitation and support to be able to engage in ACP very early on in the disease. Few participants in my study, PWD or carers, had had any information or guidance on what to expect as the dementia progressed so they felt unable to prepare for the future, in contrast with what current policy suggests.

Future policy should reflect reality but also should suggest practical measures to enable people to make ACPs if they wish. Further, more consideration is required to ensure that carer support, both practical and emotional, is available across all disease groups to fully support carers making decisions about treatment and care that are informed by the preferences of the person with dementia.

The National End of Life Care Strategy (2008) also proposed and supported the development of pathways of care that facilitated care and treatment as end of life approached (e.g. Liverpool Care Pathway, Gold Standards Framework and Preferred Priorities for Care). The most controversial of these was the Liverpool Care Pathway (LCP) for the dying patient (DH, 2013a). The LCP was an approach to care including a complex set of interventions, which aimed to improve care of the dying patient in acute hospitals and replicate the standards found in many hospices.

It was in part a response to the belief of clinicians and others that care for the dying in the acute sector was deficient (DH, 2013a). However, concerns were expressed by families who suspected that the death of their loved one had been hastened by the premature, or over-prescription of strong pain killing drugs or sedatives, and reported that these had sometimes been administered without discussion or consultation (Devlin, 2009). After several years of criticism and negative media coverage, the LCP was finally withdrawn. Many participants through the course of phases one and two of my research expressed concerns about junior medical decision making and in particular in respect of the LCP, which in the nominal groups was referred to as the 'slow count to death'. If ACP is to be of benefit in making end of life preferences known, it must be based on best evidence and not become mechanistic and rigid as was perceived to be the case for the LCP.

The National Dementia Strategy calls for steps to be taken to improve quality of life for PWD and their carers through earlier diagnosis and intervention in support of better quality [end of life] care (DH, 2009). ACP is postulated as one of the benefits of a 'timely' diagnosis, often interpreted as an early diagnosis. The benefit proposed is that if people receive their diagnosis sooner they will have more time to plan for the future, including making known their end of life care preferences.

My research indicates that this may not always work in practice, and that there are several difficulties with what the policy assumes is a simple process of articulating preferences for the future. We cannot assume that all people recently diagnosed with dementia will have the ability to consider their future options; my results demonstrated that even those who scored highly in cognitive assessment in both phases of my study struggled to think of themselves in the future. And, whilst clinicians often turn to carers to make decisions when the person with dementia has lost capacity, I have shown that carers cannot always accurately predict their

preferences. This was despite the participants in this study being from a relatively select sub-group of families affected by dementia. They were well connected with memory clinic services, and many were on the dementia research register. Even so, there was a large level of unmet need for information and carers struggling to cope with day-to-day decisions. Therefore, policy and guidance will also be required to develop approaches and interventions to support advance care planning that addresses such concerns.

7.3.3 Implications for practice

This study has identified a relative lack of knowledge and understanding among PWD and carers including the prognosis of dementia, the purpose and process of ACP, preparing for making difficult decisions in the future and deciding how these choices will be made. It has also demonstrated that carers find it wearisome enough managing the day-to-day decision making, without having to plan ahead and make decisions about possible future events. This suggests that there is a need for both targeted educational initiatives and support processes, around both the nature and course of dementia and how to plan ahead.

The clinical implications from these findings are as follows:

- i) Alongside diagnosis, clinicians should offer information on prognosis. However, as discussed earlier, it is very difficult for clinicians to know what the future might hold for each PWD and cannot discuss all possible eventualities. Equally, people may die from other disease processes before developing advanced dementia. This all adds to the complexity of prognostic discussions, yet even well validated prognostic tools, such as the Functional Assessment Staging (Reisberg, 1988), have a low predictive ability (Brown et al., 2013). However,

participants in my study had little knowledge of what the future held and spoke of wanting to know the 'milestones'. Such discussions may be better imparted as part of an on-going support package, such as offered by Admiral Nursing, rather than as a 'one-off' discussion.

- ii) Clinicians should consider holding the conversations about wishes and preferences separately with the PWD and their carer, as well as both together, wherever possible, to ensure that those of the PWD are heard and not unduly influenced by those of the carer.
- iii) Post-diagnostic counselling for families affected by dementia is not currently delivered in any consistent way in the UK and whether ACP is included in such an intervention or offered over the course of the disease is unknown. However, Admiral Nurses, and the model of care that they work to, are in a prime position to deliver an ACP intervention in their remit of post-diagnostic counselling and ongoing support of families affected by dementia. However, this would require significant investment as cost effectiveness of such an intervention would be a major concern.

7.4 Conclusion

This thesis makes an original contribution to our understanding of the issues around ACP for PWD and their carers. Whilst robust evidence for the presumed benefits of ACP is still lacking, my study furthers our understanding of the challenges that face PWD and their families in considering end of life care preferences.

Advance care planning may offer a range of benefits to PWD and their families such as initiating conversations that can lead to planning ahead and articulating wishes and preferences for care in the future but there remain significant barriers that will

need to be addressed in order to gain optimum outcomes of such an intervention. PWD find it difficult to conceive of their future selves and think about preferences for end of life care thus making it difficult, prospectively to identify future treatment choices. However, they are able to identify aspects of their current life that they value and enjoy and would wish to continue. However, when interviewed together, carers tend to override the PWD's views. So clinicians will need to ensure the preferences for care of the PWD are heard and this may involve individual interviews.

Carers' preferences for their own end of life care were influenced both by their experiences of caring for the PWD and negative media coverage of dementia and dementia care. The media content at the time of this study included the failings of the Liverpool end of life Care Pathway, and its eventual withdrawal from practice. Carers had a mistrust of such guidelines and had doubts that their expressed preferences, in the form of an ACP, would carry weight at a time when they lacked capacity to make decisions.

Dyads claimed to have a shared approach to decision making but I found that joint healthcare decision making had largely been untested until the diagnosis of dementia was made. Despite this lack of preparedness, carers are often called upon to support clinical decision making at a time when the PWD no longer has the capacity to do so. I also found that carers find the increasing burden of assuming the day-to-day decision making on behalf of the PWD wearisome which meant that they did not have the emotional energy to consider medium or long term planning. Further, both PWD and carers showed marked uncertainty about end of life treatment choices, often reflecting that they did not have enough information about potential future health states to make such decisions. However, this meant that carers could accurately predict the PWD's preferences in the here-and-now, but, at

best, were only moderately able to predict treatment choices in future hypothetical health states.

Families affected by dementia require practical and emotional support at the outset to enable them adapt to changes in usual patterns of decision making, prepare for changes ahead and ensure, where possible, that the PWD's preferences are upheld. Thus, the investigation of how best to apply ACP remains an important topic.

I have been conscious throughout that PWD, carers and health service staff have allowed me to explore the most sensitive of subject matters yet, have given of themselves freely and courageously, I hope that my study has done them justice.



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APPENDICES

Appendix 5: Phase One, Ethics approval



National Research Ethics Service **Barnet, Enfield & Haringey Local Research Ethics Committee**

R&D Dept,
Royal National Orthopaedic Hospital
Brockley Hill
Stanmore
HA7 4LP

Telephone: 020 8909 5318
Facsimile: 020 8386 7151

27 February 2009

Mrs Karen Harrison Dening
Consultant Admiral Nurse
Barnet Enfield & Haringey MH NHS Trust
D1 St Ann's Hospital
St Ann's Road
London
N15 3TH

Dear Mrs Harrison Dening

Full title of study: Is Advanced Care Planning acceptable and feasible for people with mild dementia
REC reference number: 09/H0723/2

The Research Ethics Committee reviewed the above application at the meeting held on 24 February 2009. Thank you for attending to discuss the study.

Discussion during the review

1. Concern was expressed that 2 hours participation in the nominal groups may be too much for people with mild dementia and also for their carers. You re-assured the committee that some of this time would be taken up with introductions and refreshments and in reality the maximum time required was likely to be 1 hr 30 minutes.
2. The committee sought clarification regarding the necessity to contact the GP. You explained this was a courtesy and for information only and there was no intention to review GP records. The committee suggested that this should be made clear on the Consent Form.
3. The information sheet for the nominal groups mentioned follow up telephone calls and questionnaires but there was no mention of questionnaires in the application. You confirmed that questionnaires were mentioned in error and this would be deleted from the information sheet.

Ethical opinion

The members of the Committee present gave a **favourable ethical opinion** of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The Committee agreed that all sites in this study should be exempt from site-specific

This Research Ethics Committee is an advisory committee to London Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England

assessment (SSA). There is no need to submit the Site-Specific Information Form to any Research Ethics Committee. The favourable opinion for the study applies to all sites involved in the research.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Participant Consent Form	1	26 January 2009
Participant Information Sheet	1	26 January 2009
GP/Consultant Information Sheets	1	26 January 2009
Letter of invitation to participant	1	26 January 2009
Interview Schedules/Topic Guides	1	26 January 2009
Peer Review		19 January 2009
Letter from Sponsor		29 January 2009
Covering Letter		29 January 2009
Protocol	1	26 January 2009
Investigator CV		26 January 2009
Application	1	26 January 2009

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

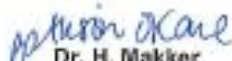
We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

09/H0723/2

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely


Dr. H. Makker
(Acting) Chair

Email: alison.okane@rnh.nhs.uk

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments "After ethical review – guidance for researchers"*

Copy to: *Mr Alan Beaton
[R&D office for NHS care organisation at lead site]*

Appendix 6: Participant Information Sheet, Nominal Groups

Barnet, Enfield and Haringey

Mental Health NHS Trust

(Version No: 02/March_2009)

Haringey MHSOP
Barnet, Enfield and Haringey Mental
Health NHS Trust
D1 St Ann's Hospital
St Ann's Road
London
N15 3TH

Tel: 020 8442 6233
Email: karen.harrison@beh-mht.nhs.uk

INFORMATION SHEET

Dear

Study Title

Nominal Groups to establish wishes and priorities for future care in people with early memory problems

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Background

The number of people with memory problems increases dramatically with age. Approximately 775,200 people in the UK are suffering from severe memory problems. This will increase to an estimate of 1.8 million by 2050.

Many people, as well as those people with memory problems may suffer from various serious medical illnesses such as pneumonia later in life, and are therefore often admitted to busy acute general hospital wards.

When requiring this sort of treatment or admission to hospital most people are able to state what their wishes and priorities for care might be. Unfortunately people with severe memory problems are often unable to express their wishes and inform health care professionals what these are.

No matter what their age or diagnosis, it should be everyone's right to receive care according to their need. At the moment, we do not always fully meet the care needs of these patients and their carers/relatives. This could be improved by people with

memory problems stating early on in their illness what they would or would not want later on, when no longer able to clearly say. This study will attempt to develop a process that will enable people that have recently been diagnosed with memory problems to be able to discuss what they wish or prioritise for their future care and could be used to develop and advanced care plan. Our ultimate aim is to improve the quality of care for people with memory problems and help them to access the care they need and wish for later in life.

Why me?

After a discussion with the East or West Community Mental Health Team, Memory Clinic or Admiral Nurse Team you have been chosen as a person with early memory problems or are their carer/relative.

All participants will be assigned into one of 3 groups:

Group 1

5 to 8 people with memory problems

Group 2

5 to 8 carers of a person with memory problems

Group 3

4 to 5 couples of both people with memory problems *and* their carers

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What will happen to me if I take part?

We would like to talk to each group in a private group room within the Memory Clinic at St Ann's Hospital; many of you may be familiar with the place and already have attended the Memory Clinic or perhaps an outpatient appointment there.

All participants, which ever group you are in, will be offered the opportunity of discussing your wishes and priorities for their future care and develop a 'top five list' that can later be used by others in a similar situation to help them to plan for their future.

As well as the researcher leading the group there will also be an Admiral Nurse present to help with any explanations or offer any assistance required by the group members.

The focus groups will be audio recorded so we can capture all that is said, this will then be typed up so that no names or individuals can be identified. All data will be securely and safely stored in the university department on a specially created database, after this all the tapes will be destroyed.

What do I have to do?

We will ask everyone to attend only one of the three group sessions mentioned. Each session will last a total of two hours to include general introductions and refreshments etc. The actual work and recording will last for about 1 hour and no more than 1 ½ hours. The researcher will facilitate discussions with the help of an Admiral Nurse in helping you to identify and discuss your wishes and priorities for future care.

What is the treatment being tested?

We are trying to improve care and services received by people with dementia. It is important that people with dementia receive care as their illness progresses that aim to meet their personal beliefs and wishes when well. We do not yet know how acceptable and useful people with dementia find advance care planning to be, so we would like to try using it with some people with dementia problems and their carers/relatives.

What are the possible benefits of taking part?

We have designed the study and the advance care planning information carefully and hope that it will help improve the care for older people with dementia as their illness progresses. Because this is a new to people with dementia when newly diagnosed, we do not yet whether it will help. Therefore we cannot promise that this study will directly help you but the information we get will help improve services for people with dementia in the future.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed.

Our contact number is: 020 8442 6233

Will my taking part in the study be kept confidential?

Yes. All the information about your participation in this study will be kept confidential.

Contact Details:

For further information about the study or for any concerns during the study please contact:

Karen Harrison Denning
Consultant Admiral Nurse
020 8442 6233

If you are considering participation, please continue to read the additional information below before making any decision.

What will happen if I don't want to carry on with the study?

That is fine, just let the researchers know and they will stop and allow you to leave the group. If you do not want us to use the information you have given us, just let us know and it will be destroyed. This will not affect in any way any future care.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with the researcher who will do their best to answer your questions (Contact number 020 8442 6233). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure.

If you wish to go further and complain about any aspect of the way you have been approached or treated during the course of the study, you should write or get in touch with the Complaints Manager, at the Mental Health Unit, K1, St Ann's Hospital, St Ann's Road, London N15 3TH (telephone number: 020 8442 5884).

In the highly unlikely event that something does go wrong and you are harmed during the research study University College London (the Research Governance sponsor of this study) has arrangements in place for non-negligent harm (no-fault compensation). If you are harmed and this is due to someone's negligence then you may have grounds for a legal action for compensation but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in this study be kept confidential?

Your name and contact details will be removed from any data that are stored concerning you or the person you are caring for. The recordings of the group participants will be made anonymous (given a study number or letter) and will be stored securely on our research database and offices and with only the research team and authorised staff having access. The group discussions will be entered in an anonymous form on to a secure computer and combined with the views of all the other people in the groups. This will give an overall view of the wishes and priorities for both carers and people with early memory problems. Using this information we hope to develop a process for aiding advance care planning for all people with early memory problems.

Our procedures for handling, processing, storage and destruction of data are compliant with the Data Protection Act 1998.

What will happen to the results of the research study?

The results of the study will be used to assist people with early memory problems to be able to identify their wishes and priorities for their future care. We also hope to publish in scientific journals any results so that the findings can be taken on throughout the country. You will not be identified in any report/publication.

Who is organising and funding the research?

The study is being carried out as part of a doctorate level degree (PhD) at University College, London and Barnet, Enfield and Haringey Mental Health NHS Trust.

Who has reviewed the study?

This study was given a favourable ethical opinion for conduct in the NHS by Barnet Enfield and Haringey Local Research Ethics Committee on 24 February 2009.

You can keep a copy of this information sheet and a signed consent form.

Thank you for taking time to read this sheet.

Appendix 7: Consent Form, Nominal Groups

Barnet, Enfield and Haringey 
Mental Health NHS Trust

(Version No: 02/March_2009)

Haringey MHSOP
Barnet, Enfield and Haringey Mental
Health NHS Trust
D1 St Ann's Hospital
St Ann's Road
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N15 3TH

Tel: 020 8442 6233
Email: karen.harrison@beh-mht.nhs.uk

CONSENT FORM

Study Title

Nominal Groups to establish wishes and priorities for future care in people with early memory problems

Participant Identification Number for this study:

Name of Principal investigator: Karen Harrison Dening

Please initial box

1. I confirm that I have read and understood the information sheet dated (Version 02/March_09) for the above study and have had the opportunity to ask questions.
2. I confirm that I have had sufficient time to consider whether or not want to be included in the study
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
4. I understand that my GP will be notified for information purposes only of my participation in this study (Person with memory problems).

CONSENT FORM (Version No: 02/March_2009 continued)

Title of project:

Nominal Groups to establish wishes and priorities for future care in people with early memory problems

Patient Identification Number for this study:

Name of participant:	Signature:	Date:
Name of person taking consent: <i>(if different from researcher)</i>	Signature:	Date:
Name of researcher: <i>(to be contacted if there are any problems)</i>	Signature:	Date:

1 form for participant

1 to be kept as part of the study documentation

1 to be kept with hospital notes (person with memory problems)

Appendix 8: GP letter, Nominal Groups

Barnet, Enfield and Haringey Mental Health NHS Trust

(Version No: 01/February_2009)

Haringey MHSOP
Barnet, Enfield and Haringey Mental Health
NHS Trust
D1 St Ann's Hospital
St Ann's Road
London
N15 3TH

Tel: 020 8442 6233
Email: karen.harrison@behmht.nhs.uk

GP Address Date

Dear Dr

Participation in research: study title: Nominal Groups to establish wishes and priorities for future care in people with early memory problems

This is to inform you that your patient ([name](#); [address](#); [dob](#)) has consented to participate in the above study taking place within BEH Mental Health Trust. The study is being conducted as part of a doctorate level study at University College Hospital within Barnet Enfield & Haringey Mental Health NHS Trust and aims to identify the wishes and priorities for future care of people with early dementia and their carers.

People with a diagnosis of early dementia and their carers will be recruited from caseloads of East and West Community Mental Health Teams, the Memory Clinic and the Admiral Nursing Service to take part in one of three nominal groups. The nominal groups aim to facilitate participants to identify what are important wishes and priorities for them in their receipt of care in the future. Information will be available on advance care planning if participants wish to access it.

If you would like any further information on the study, please do not hesitate to contact me.

Yours sincerely

Karen Harrison
Consultant Admiral Nurse

Appendix 9: Nominal Group Schedule

Version 01/February_2009

Nominal Group Schedule

Researcher starts by “thanking participants for agreeing to be part of this nominal group – there will be two other similar groups that will be run on different days”.

Stress that the group is about improving our understanding of what people with early dementia see as important factors that influence the care they would want in the future in later stages of the illness when they may not be able to say so.

If you feel that you need to stop or leave the room please tell me.

We are tape recording the discussions today and whatever you talk about will be anonymised for the purposes of the study.

We are here to think about what your wishes and priorities might be for you future care – to find out what is important now and in the future. This is often called advance care planning.

We would first of all like to give you an idea about what advance care planning is.

Brief outline of what is ‘advance care planning’:

Why make our wishes and priorities known?

People with dementia are at risk of losing the ability to make their own decisions as the illness progresses.

People who have dementia, or who are worried that they may develop it in future, are often concerned about how decisions about their future care and medical treatment would be made if they lost the ability to decide for themselves. They may also fear that they would be forced to have treatments they did not want or not receive treatments they would have wanted (AS Fact sheet 463).

Law

There is a law (Mental Capacity Act 2005) that gives you the statutory right to state what forms of care and treatment you would or would not like to receive should you become unable to decide for yourself in the future

- To actually state what your future wishes might or might not be*
- To actually state what your priorities might be*

If at any time you are unable to say what you would want.

Currently for most people with dementia it is often down to family or friends to try and advise professionals about the sort of treatments they would or would not have wanted. This may be distressing – having to make decisions on behalf of someone else or the views perhaps expressed are their own and not necessarily those of the person with dementia.

So advance care planning discussions can be very helpful.

In the session today I want us to start to think about our future care wishes and priorities are – what is important to us now and in the future?

Stage 1 - Generating ideas

The first stage in the group is to all have a few moments to think about what these wishes and priorities might be. You all have some blank sheets of paper and a pen and I want us to spend the first 5-10 minutes simply writing down on each piece of paper one thing that you think is a wish or priority that would be important to you if you were no longer able to say.

e.g. It may be a priority to you that you continue to go to church each Sunday – that your spiritual well being is a high priority

(Co researcher offer assistance and guidance where necessary to ensure the task is understood – without influencing generation of ideas)

Stage 2 – Discussion

In this stage we will collect in all your pieces of paper and we will discuss each idea in turn – all ideas are very important.

We want to talk about each idea and clarify what is being said.

Stage 3 – Further generation of ideas

Some of the ideas we have shared together may have prompted you to think of other things that are important to you. We will take a few more minutes to allow you to write down any further wishes and priorities.

(Co researcher ensure sufficient paper is available)

Stage 4 – Discussion and sorting to themes

Now we have time to generate some ideas we can discuss them all and start to group these ideas – there may be some that are the same or are similar.

(Co researcher places each piece of paper/idea onto a flip chart paper and notes the theme at the top. Each with the same theme will be pinned respectively to the appropriate paper)

Stage 5 – Ranking

We have generated (n) wishes and priorities as you can see from the charts on the walls. (Researcher to read each out again)

The final stage is to now place each of these in the order that has at the top – number 1 – the one that is MOST important to you; then number 2 – the second most important – and so on.

Stress that there are no right or wrong answers and that the priorities and wishes are a very personal thing and is one of many aspects that makes us individual

(Researcher hands out a sheet with 5 boxes numbered one to 5 to each participant. Co researcher will offer support where required without influencing ranking)

Collect all ranking sheets in

Researcher will inform participants that all the information generated from today will be collated with that from the other groups and used to develop a framework and a tool to assist people with a diagnosis of early dementia to be able to consider what their wishes and priorities might be and so enable them to develop their own advance care plan.

If any participant wishes any further information on advance care planning and advance directives there will be information available:

Alzheimer Society Fact sheet 463 – Advance Decision

Also available will be access to an educational session on Advance Care Planning run by the Admiral Nursing Team.

Thank all participants for taking part in this group.

Ranking sheet

Participant No:	
1 Most Important	
2	
3	
4	
5 Least Important	

Appendix 10: Information sheet for person with dementia



Barnet, Enfield and Haringey 
Mental Health NHS Trust



Participant Information Sheet
(Version_3_Feb_2012)

Karen Harrison Dening
Head of Nursing, Admiral Nursing
Dementia UK
6 Camden High Street
London NW1 0JH

Tel: 020 7874 7200
Email: karen.harrison-dening@dementiauk.org

Study Title: How well do people with dementia and memory problems and their family carers agree on preferences for life sustaining treatment(s) at end of life and which factors influence this?

(Student PhD Project)

My name is Karen Harrison Dening and I am an Admiral Nurse (specialist nurse working with families affected by dementia) and am undertaking PhD studies at University College London. As a final part of this work I would like to invite you and the person who cares for you to take part in my research. Before you decide, it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. I will contact you after seven days to see if you want to take part. Please let me know if you need longer.

Background

The number of people with dementia and memory problems increases dramatically with age. Approximately 775,200 people in the UK are suffering from dementia and memory problems. This will increase to an estimate of 1.8 million by 2050.

Many people, as well as those people with dementia and memory problems may suffer from serious medical illnesses, such as pneumonia, later in life and are therefore often admitted to general hospital wards.

When admitted to hospital, most people are able to state what their wishes and priorities for care might be. Unfortunately people with dementia and severe memory problems are often unable to express their wishes and inform health care professionals what sorts of treatment they would like.

At the moment, we do not always fully meet the care needs of people with dementia and memory problems. This could be improved if people with dementia and memory problems stated early on in their illness what sorts of medical treatments they would or would not want in the future. In reality, family carers are often required to represent the views of the person with dementia and memory problems. In this

study we would like to see how well people with dementia and memory problems and their carers agree when making choices about medical treatments.

Study Aim

My ultimate aim is to improve the quality of care for people with dementia and memory problems and help them to make decisions about the care they need and wish for later in life.

Why have I been chosen?

After a discussion with Clinical Team you have been chosen as a person that has dementia or memory problems.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What will the project involve?

I would like to interview each patient and their carer; this can either be in a private room within the hospital or clinic or within your own home, you can choose. If you agree to be involved you will only be asked to meet me for one interview.

I will interview both you and your relative/carer separately. The two interviews together will last approximately 1 to 1 ½ hours. I will ask you some general questions about your memory, your previous education and your family relationships. I will then present you with three different situations about care and treatment at end of life and ask you what you think and feel about them.

What are the possible benefits of taking part?

I have designed the study carefully and hope that it will help improve the care for people with dementia and memory problems as their illness progresses. It may help you to think about what your care choices may be in the future. If you would like to do this in more depth we can direct you to professionals who can help you with this. We cannot promise that this study will directly help you but the information we obtain will help improve services for people with dementia and memory problems in the future.

Will my taking part in the study be kept confidential?

Yes. All information collected about you during the course of the research will be kept strictly confidential. Any information about you will have all identifiable information removed so that you cannot be recognised from it. This anonymous information will be collected, stored handled and processed by the researcher at University College London.

Our procedures for handling, processing, storage and destruction of data are compliant with the Data Protection Act 1998.

What will happen if I don't want to carry on with the study?

That is fine, just let the researcher know and they will stop the interview. If you do not want me to use the information you have given me, just let me know and it will be destroyed. This will not affect any future care you may receive.

What if there is a problem?

If you have a concern about any aspect of this study, please speak with me and I will do my best to answer your questions (Contact number 020 7874 7200, Monday to Friday 9.00 – 5.00, or alternatively a message can be left if I am unavailable).

If you remain unhappy and wish to complain formally about any aspect of the way you have been approached or treated during the course of the study, you should write or get in touch with the Complaints Manager, Admin Block, Room 14, St Ann's Hospital, St Ann's Road, London N15 3TH (telephone number: 020 8442 5884).

In the highly unlikely event that something does go wrong and you are harmed during the research study University College London (the Research Governance sponsor of this study) has arrangements in place for non-negligent harm (no-fault compensation). If you are harmed and this is due to someone's negligence then you may have grounds for a legal action for compensation but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

What will happen to the results of the research study?

The results of this study will be shared with other hospitals and organisations. They will also be presented at conferences and published in medical journals. If you wish to have a copy of the study results sent to you, please let me know. It will not be possible to identify individuals who have participated in the study.

Who is organising and funding the research?

The study is being carried out as part of a PhD at University College, London and Barnet, Enfield and Haringey Mental Health NHS Trusts.

Who has reviewed the study?

This study has been peer reviewed and was given a favourable opinion for conduct in the NHS by the NRES Committee South East Coast - Surrey on 17th January 2012.

You can keep a copy of this information sheet and a signed consent form.

Thank you for taking time to read this sheet. For further information about the study or for any concerns during the study please contact: **Karen Harrison Dening, Head of Nursing, Admiral Nursing, Dementia UK, 020 7874 7200**

Appendix 11: Information sheet for carer



Barnet, Enfield and Haringey 
Mental Health NHS Trust



Carer Information Sheet
(Version_3_Feb_2012)

Karen Harrison Denning
Head of Nursing, Admiral Nursing
Dementia UK
6 Camden High Street
London NW1 0JH

Tel: 020 7874 7200

Email:
karen.harrisondening@dementiauk.org

Study Title: How well do people with dementia and memory problems and their family carers agree on preferences for life sustaining treatment(s) at end of life and which factors influence this?

(Student PhD Project)

Invitation

My name is Karen Harrison Denning and I am an Admiral Nurse (specialist nurse working with families affected by dementia) and am undertaking PhD studies at University College London. As a final part of this work I would like to invite you and the person you care for to take part in my research. Before you decide, it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. I will contact you after seven days to see if you want to take part. Please let me know if you need longer.

Background

The number of people with dementia increases dramatically with age. Approximately 775,200 people in the UK are suffering from dementia and severe memory problems. This will increase to an estimate of 1.8 million by 2050.

Many people, as well as those people with dementia and memory problems may suffer from serious medical illnesses, such as pneumonia, later in life and are therefore often admitted to general hospital wards. When admitted to hospital, most people are able to state what their wishes and priorities for care might be. Unfortunately people with dementia and severe memory problems are often unable to express their wishes and inform health care professionals what sorts of treatment they would like.

At the moment, we do not always fully meet the care needs of people with dementia and memory problems. This could be improved if people with dementia and memory problems stated early on in their illness what sorts of medical treatments they would or would not want in the future. In reality, family carers are often required to represent the views of the person with dementia or memory problems. In this study we would

like to see how well people with dementia and memory problems and their carers agree when making choices about medical treatments.

Study aim

My ultimate aim is to improve the quality of care for people with dementia and memory problems and help them to make decisions about the care they need and wish for later in life.

Why have I been chosen?

After a discussion with Clinical Team you have been chosen as a person for cares for someone with dementia or memory problems.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What will the project involve?

I would like to interview each patient and their carer; this can either be in a private group room within the hospital or clinic or within your own home, you can choose. If you agree to be involved you will only be asked to meet me for one interview.

I will interview both you and the person you care for separately. The two interviews together will last approximately 1 to 1 ½ hours. I will ask you some general questions about caring, your previous education and your family relationships. I will then present you with three different situations about care and treatment at end of life and ask you what you think the person you care for might prefer in these situations.

What are the possible benefits of taking part?

I have designed the study carefully and hope that it will help improve the care for people with dementia and memory problems as their illness progresses. I cannot promise that this study will directly help you or the person you care for but the information we get will help improve services for people with dementia and memory problems in the future.

Will my taking part in the study be kept confidential?

Yes. All information collected about you during the course of the research will be kept strictly confidential. Any information about you will have all identifiable information removed so that you cannot be recognised from it. This anonymous information will be collected, stored handled and processed by the researcher at University College London. Our procedures for handling, processing, storage and destruction of data are compliant with the Data Protection Act 1998.

What will happen if I don't want to carry on with the study?

That is fine, just let the researcher know and they will stop the interview. If you do not want me to use the information you have given me, just let me know and it will be destroyed. This will not affect any future care the person with dementia or you as their carer receive.

What if there is a problem?

If you have a concern about any aspect of this study, please speak with me and I will do my best to answer your questions (Contact number 020 7874 7200, Monday to Friday 9.00 – 5.00, or alternatively a message can be left if I am unavailable).

If you remain unhappy and wish to complain formally about any aspect of the way you have been approached or treated during the course of the study, you should write or get in touch with the Complaints Manager, Admin Block, Room 14, St Ann's Hospital, St Ann's Road, London N15 3TH (telephone number: 020 8442 5884).

In the highly unlikely event that something does go wrong and you are harmed during the research study University College London (the Research Governance sponsor of this study) has arrangements in place for non-negligent harm (no-fault compensation). If you are harmed and this is due to someone's negligence then you may have grounds for a legal action for compensation but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

What will happen to the results of the research study?

The results of this study will be shared with other hospitals and organisations. They will also be presented at conferences and published in medical journals. If you wish to have a copy of the study results sent to you, please let me know. It will not be possible to identify individuals who have participated in the study.

Who is organising and funding the research?

The study is being carried out as part of a PhD at University College, London and Barnet, Enfield and Haringey Mental Health NHS Trusts.

Who has reviewed the study?

This study has been peer reviewed and was given a favourable opinion for conduct in the NHS by the NRES Committee South East Coast - Surrey on 17th January 2012.

You can keep a copy of this information sheet and a signed consent form.

Thank you for taking time to read this sheet. For further information about the study or for any concerns during the study please contact:

Karen Harrison Denning
Head of Nursing, Admiral Nursing
Dementia UK, 020 7874 7200

Appendix 12: Consent form for person with dementia



Barnet, Enfield and Haringey
Mental Health NHS Trust



**Participant Consent
Form**

(Version_3_Feb_2012)

Karen Harrison Dening
Lead Practice Development Admiral Nurse
Dementia UK
6 Camden High Street
London NW1 0JH
Tel: 020 7874 7200

Email: karen.harrisondening@dementiauk.org

Participant Identification Number:

Name of Principal investigator: Karen Harrison Dening

Title of project: How well do people with dementia and memory problems and their family carers agree on preferences for life sustaining treatment(s) at end of life and which factors influence this?

(Student PhD)

Please initial box

- 1 I confirm that I have read and understood the information sheet (version3_Feb_2012) for the above study and have had the opportunity to ask questions.
- 2 I confirm that I have had sufficient time to consider whether or not I want to be included in the study
- 3 I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
- 4 I understand that sections of any of my medical notes may be looked at by responsible individuals from University College London or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records.
- 5 I understand that my GP will be notified for information purposes only of my participation in this study.
- 6 I can choose to be interviewed in my own home if I wish.
- 7 I agree to take part in the above study.

This form continues onto a second page.

CONSENT FORM continued

Participant Identification Number:

Title of project: How well do people with dementia and memory problems and their family carers agree on preferences for life sustaining treatment(s) at end of life and which factors influence this?

(Student PhD)

_____	_____	_____
Name of participant	Date	Signature

_____	_____	_____
Researcher	Date	Signature

1 form for participant

1 to be kept as part of the study documentation

1 to be kept with hospital notes

Appendix 13: Consent form for carer



Barnet, Enfield and Haringey
Mental Health NHS Trust



Carer Consent Form
(Version_3_Feb_2012)

Karen Harrison Dening
Lead Practice Development Admiral Nurse
Dementia UK
6 Camden High Street
London NW1 0JH
Tel: 020 7874 7200
Email: karen.harrisondening@dementiauk.org

Participant Identification Number:

Name of Principal investigator: Karen Harrison Dening

Title of project: How well do people with dementia and memory problems and their family carers agree on preferences for life sustaining treatment(s) at end of life and which factors influence this?

(Student PhD)

Please initial box

1. I confirm that I have read and understood the information sheet (version_3_Feb_2012) for the above study and have had the opportunity to ask questions.
2. I confirm that I have had sufficient time to consider whether or not I want to be included in the study
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my care or legal rights being affected.
4. I agree to take part in the above study.

This form continues onto a second page.

Title of project: How well do people with dementia and memory problems and their family carers agree on preferences for life sustaining treatment(s) at end of life and which factors influence this?

(Student PhD)

Name of participant

Date

Signature

Researcher

Date

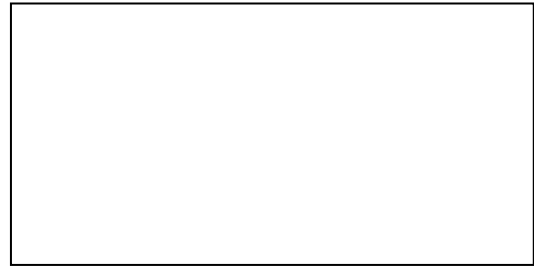
Signature

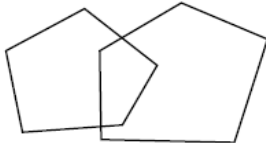
1 form for participant

1 to be kept as part of the study documentation

Appendix 14: Mini Mental State Examination

**MINI MENTAL STATE
EXAMINATION
(MMSE)**



ONE POINT FOR EACH ANSWER	DATE				
ORIENTATION					
Year Month Day Date Time	___/5	___/5	___/5	___/5	___/5
Country Town District Hospital Ward	___/5	___/5	___/5	___/5	___/5
REGISTRATION					
Examiner names 3 objects (eg apple, table, penny) Patient asked to repeat (1 point for each correct). THEN patient to learn the 3 names repeating until correct.	___/3	___/3	___/3	___/3	___/3
ATTENTION AND CALCULATION					
Subtract 7 from 100, then repeat from result. Continue 5 times: 100 93 86 79 65 Alternative: spell "WORLD" backwards - dlrow.	___/5	___/5	___/5	___/5	___/5
RECALL					
Ask for names of 3 objects learned earlier.	___/3	___/3	___/3	___/3	___/3
LANGUAGE					
Name a pencil and watch.	___/2	___/2	___/2	___/2	___/2
Repeat "No ifs, ands, or buts".	___/1	___/1	___/1	___/1	___/1
Give a 3 stage command. Score 1 for each stage. Eg. "Place index finger of right hand on your nose and then on your left ear".	___/3	___/3	___/3	___/3	___/3
Ask patient to read and obey a written command on a piece of paper stating "Close your eyes".	___/1	___/1	___/1	___/1	___/1
Ask the patient to write a sentence. Score if it is sensible and has a subject and a verb.	___/1	___/1	___/1	___/1	___/1
COPYING					
Ask the patient to copy a pair of intersecting pentagons:					
	___/1	___/1	___/1	___/1	___/1
TOTAL	___/30	___/30	___/30	___/30	___/30

Appendix 15: Zarit Burden Interview

The Zarit Burden Interview

	Never	Rarely	Some times	Quite frequently	Nearly always
1. Do you feel that your relative asks for more help than he/she needs?	0	1	2	3	4
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4. Do you feel embarrassed over your relative's behaviour?	0	1	2	3	4
5. Do you feel angry when you are around your relative?	0	1	2	3	4
6. Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?	0	1	2	3	4
7. Are you afraid what the future holds for your relative?	0	1	2	3	4
8. Do you feel your relative is dependent on you?	0	1	2	3	4
9. Do you feel strained when you are around your relative?	0	1	2	3	4
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
11. Do you feel that you don't have as much privacy as you would like	0	1	2	3	4

because of your relative?					
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
13. Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4
15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0	1	2	3	4
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4
18. Do you wish you could leave the care of your relative to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20. Do you feel you should be doing more for your relative?	0	1	2	3	4
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4

Instructions for use:

The questions above reflect how persons sometimes feel when they are taking care of another person. After each statement, circle the word that best describes how often you feel that way. There are no right or wrong answers.

Appendix 16: Kessler Psychological Distress Scale (K10)

Carer ID:

Date

Kessler Psychological Distress Scale (K10)

This is a 10-item questionnaire intended to yield a global measure of distress based on questions about anxiety and depressive symptoms that a person has experienced in the most recent 4 week period.

K10

For all questions, please fill in the appropriate response circle. Fill in the circles like this: ●
Please do not tick or cross the circles.

In the past 4 weeks:

None of the time	A little of the time	Some of the time	Most of the time	All of the time
---------------------	-------------------------	---------------------	---------------------	--------------------

- | | |
|--|-------------------|
| 1. About how often did you feel tired out for no good reason? | ○ — ○ — ○ — ○ — ○ |
| 2. About how often did you feel nervous? | ○ — ○ — ○ — ○ — ○ |
| 3. About how often did you feel so nervous that nothing could calm you down? | ○ — ○ — ○ — ○ — ○ |
| 4. About how often did you feel hopeless? | ○ — ○ — ○ — ○ — ○ |
| 5. About how often did you feel restless or fidgety? | ○ — ○ — ○ — ○ — ○ |
| 6. About how often did you feel so restless you could not sit still? | ○ — ○ — ○ — ○ — ○ |
| 7. About how often did you feel depressed? | ○ — ○ — ○ — ○ — ○ |
| 8. About how often did you feel that everything is an effort? | ○ — ○ — ○ — ○ — ○ |
| 9. About how often did you feel so sad that nothing could cheer you up? | ○ — ○ — ○ — ○ — ○ |
| 10. About how often did you feel worthless? | ○ — ○ — ○ — ○ — ○ |

Today's date / /
Day Month Year

**Appendix 17: Quality of the Care-Giving Relationship person with dementia
version**

Quality of the Care-giving Relationship (QCPR) (Patient_version1_Feb_2012)

Please think about your relationship with the person who is caring for you and answer the following questions.

1. My relative and I often spend time together in an enjoyable way

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

2. My relative and I often disagree

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

3. There is a big distance in the relationship between my relative and myself

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

4. My relative and I accept each other as we are

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

5. If there are problems my relative and I can usually resolve these easily

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

6. I get on well with my relative

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

7. My relative and I are tender towards each other

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

8. My relative often annoys me

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

9. I feel very good if I am with my relative

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

10. My relative and I often try to impose our opinions on each other

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

11. I blame my relative for the cause of my problems

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

12. My relative and I appreciate each other as people.

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

13. My relative does not appreciate enough what I do for him/her

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

14. I am always glad to see him/her if I have not seen him/her for some time.

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

Appendix 18: Quality of the Care-Giving Relationship carer version

Quality of the Care-giving Relationship (QCPR) (Carer_version1_Feb_2012)

Please think about your relationship with the person who is caring for you and answer the following questions.

1. My relative and I often spend time together in an enjoyable way

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

2. My relative and I often disagree

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

3. There is a big distance in the relationship between my relative and myself

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

4. My relative and I accept each other as we are

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

5. If there are problems my relative and I can usually resolve these easily

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

6. I get on well with my relative

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

7. My relative and I are tender towards each other

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

8. My relative often annoys me

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

9. I feel very good if I am with my relative

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

10. My relative and I often try to impose our opinions on each other

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

11. I blame my relative for the cause of my problems

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

12. My relative and I appreciate each other as people.

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

13. My relative does not appreciate enough what I do for him/her

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

14. I am always glad to see him/her if I have not seen him/her for some time.

Totally disagree	Disagree	Not sure	Agree	Totally agree
1	2	3	4	5

Appendix 19: Life Support Preferences Questionnaire

LIFE SUPPORT PREFERENCE QUESTIONNAIRE (LSPQ) – Patient version

I will describe 3 different health conditions.

I want you to IMAGINE as best you can that you are in that health condition. I will then ask you about your choices for medical treatments for these 3 different conditions.

Let me tell you a little bit about each medical treatment.

[Interviewer: present a laminated card (A) with the following treatment descriptions to the participant and read aloud with him/her].

1. Antibiotics: Doctors use these medicines to treat serious infections (e.g., pneumonia). Without antibiotics, serious infections can cause life-threatening complications or death.

2. Cardiopulmonary Resuscitation (CPR): Doctors use cardiopulmonary resuscitation, or CPR, when a person's heart stops beating or a person stops breathing. Doctors press on the chest to help pump blood, and use artificial breathing. Artificial breathing means the doctor puts a tube in the windpipe. Then, a machine breathes for the patient through the tube. Patients usually get medicines by vein. Patients often need an electrical shock to help restart the heartbeat. Without CPR, the heart will not start beating again, and the patient will die.

3. Artificial Feeding and Fluids: Doctors use artificial feeding and fluids when people are unable to take enough food and water to stay alive. The food goes through a feeding tube. Usually, the feeding tube goes through the skin into the stomach. Without this treatment, patients die within 7-10 days.

Again, please **imagine** as best you can how you would feel **if** you had one of the medical conditions I describe. I will then ask you how much you would want to receive the four different treatments using this scale.

[Interviewer: Give participant laminated card with scale B]

1. I definitely would not want this treatment.
2. I probably would not want this treatment.
3. I am unsure if I would want this treatment.
4. I probably would want this treatment.
5. I definitely would want this treatment.

PLEASE REMEMBER THAT WHAT YOU SAY TO ME TODAY IS **JUST FOR OUR RESEARCH**, NOTHING YOU SAY HERE WILL BECOME PART OF A LEGALLY BINDING DOCUMENT.

[When ready to begin, commence LSPQ]:

Patient ID:

Date:

SCENARIO 1:

Imagine you are in your current health, in other words, the way you are feeling now:

A. **Imagine if** you developed a serious infection, like pneumonia, would you want to use antibiotics to treat the infection?

1____ Definitely do not want

2____ Probably do not want

3____ Unsure

4____ Probably want

5____ Definitely want

B. **Imagine if** your heart stopped beating or you stopped breathing, would you want to receive cardiopulmonary resuscitation?

1____ Definitely do not want

2____ Probably do not want

3____ Unsure

4____ Probably want

5____ Definitely want

C. **Imagine if** for whatever reason you are unable take in food or water by mouth. Would you want artificial feeding and fluids?

1____ Definitely do not want

2____ Probably do not want

3____ Unsure

4____ Probably want

5____ Definitely want

Patient ID:

Date:

SCENARIO 2:

Imagine you have suffered a severe stroke and have been in a coma for six weeks. In the opinion of your doctor, you have NO CHANCE of regaining awareness or the ability to think, reason, and remember. Your current physical condition is stable, but will slowly decline over time. You rely on others for help with feeding, bathing, dressing, and toileting. You may live in this condition for several years.

A. **Imagine if** you developed a serious infection, like pneumonia, would you want to use antibiotics to treat the infection?

1____ Definitely do not want

2____ Probably do not want

3____ Unsure

4____ Probably want

5____ Definitely want

B. **Imagine if** your heart stopped beating or you stopped breathing, would you want to receive cardiopulmonary resuscitation?

1____ Definitely do not want

2____ Probably do not want

3____ Unsure

4____ Probably want

5____ Definitely want

C. **Imagine if** in this condition you are unable take in food or water by mouth. Would you want artificial feeding and fluids?

1____ Definitely do not want

2____ Probably do not want

3____ Unsure

4____ Probably want

5____ Definitely want

Patient ID:

Date:

SCENARIO 3:

Imagine you have advanced cancer which has spread to other areas. **Imagine** you are tired and weak, requiring some help with household chores. **IMAGINE YOU HAVE PAIN THAT REQUIRES THE CONSTANT USE OF MEDICATION.** In the opinion of your doctor, you have no chance of recovery. Your doctor estimates that you have about six months to live.

A. **Imagine if** you developed a serious infection, like pneumonia, would you want to use antibiotics to treat the infection?

1____ Definitely do not want

2____ Probably do not want

3____ Unsure

4____ Probably want

5____ Definitely want

B. **Imagine if** your heart stopped beating or you stopped breathing, would you want to receive cardiopulmonary resuscitation?

1____ Definitely do not want

2____ Probably do not want

3____ Unsure

4____ Probably want

5____ Definitely want

C. **Imagine if** your condition becomes such that you lose the ability to take in food or water by mouth, would you want artificial feeding and fluids?

1____ Definitely do not want

2____ Probably do not want

3____ Unsure

4____ Probably want

5____ Definitely want

LIFE SUPPORT PREFERENCE QUESTIONNAIRE (LSPQ) – Family carer version

Sometimes people can't tell their choices for medical treatments because they are very sick. When this happens, doctors ask family or friends to help make the right choices for the patient. The right choices for a patient are the ones that the patient would have made for him/herself. Soon I will describe 3 different health conditions.

For each condition please try to imagine that (PATIENT'S NAME) is in that health condition. I will then ask you to predict as best you can the kind of medical treatments you think (PATIENT'S NAME) would want in each health condition.

Let me tell you a little bit about each medical treatment.

[Interviewer: present a laminated card (A) with the following treatment descriptions to the participant and read aloud with him/her].

1. Antibiotics: Doctors use these medicines to treat serious infections (e.g., pneumonia). Without antibiotics, serious infections can cause life-threatening complications or death.
2. Cardiopulmonary Resuscitation (CPR): Doctors use cardiopulmonary resuscitation, or CPR, when a person's heart stops beating or a person stops breathing. Doctors press on the chest to help pump blood, and use artificial breathing. Artificial breathing means the doctor puts a tube in the windpipe. Then, a machine breathes for the patient through the tube. Patients usually get medicines by vein. Patients often need an electrical shock to help restart the heartbeat. Without CPR, the heart will not start beating again, and the patient will die.
3. Artificial Feeding and Fluids: Doctors use artificial feeding and fluids when people are unable to take enough food and water to stay alive. The food goes through a feeding tube. Usually, the feeding tube goes through the skin into the stomach. Without this treatment, patients die within 7-10 days.

[Interviewer: Give participant laminated card with scale B]

Again, please imagine as best you can how (PATIENT'S NAME) would feel in each health condition I describe. I will then ask you to decide how much you think (PATIENT'S NAME) would want to receive each of the four treatments using this scale

1. He/she definitely would not want this treatment.
2. He/she probably would not want this treatment.
3. I am unsure if he/she would want this treatment.
4. He/she probably would want this treatment.
5. He/she definitely would want this treatment.

Before we begin, please remember that **WHAT YOU TELL ME TODAY IS JUST FOR OUR RESEARCH. NOTHING YOU SAY HERE WILL BECOME PART OF A LEGALLY BINDING DOCUMENT.**

[When ready to begin, commence LSPQ]:

Carer ID:

Date:

SCENARIO 1:

(PATIENT'S NAME) is in his/her current health, in other words, the way s/he is feeling now:

A. If **(PATIENT'S NAME)** developed a serious infection, like pneumonia, would s/he want to use antibiotics to treat the infection?

1____ Definitely would not want

2____ Probably would not want

3____ Unsure

4____ Probably would want

5____ Definitely would want

B. If **(PATIENT'S NAME)**'s heart stopped beating or s/he stopped breathing, would s/he want to receive cardiopulmonary resuscitation?

1____ Definitely would not want

2____ Probably would not want

3____ Unsure

4____ Probably would want

5____ Definitely would want

C. If for whatever reason **(PATIENT'S NAME)** is unable take in food or water by mouth. Would s/he want artificial feeding and fluids?

1____ Definitely would not want

2____ Probably would not want

3____ Unsure

4____ Probably would want

5____ Definitely would want

Carer ID:

Date:

SCENARIO 2:

(PATIENT'S NAME) has suffered a severe stroke and has been in a coma for six weeks. In the opinion of his/her doctor, s/he has NO CHANCE of regaining awareness or the ability to think, reason, and remember. **(PATIENT'S NAME)**'s current physical condition is stable, but will slowly decline over time. S/he must rely on others for help with feeding, bathing, dressing, and toileting. S/he may live in this condition for several years.

A. If **(PATIENT'S NAME)** developed a serious infection, like pneumonia, would s/he want to use antibiotics to treat the infection?

1____ Definitely would not want

2____ Probably would not want

3____ Unsure

4____ Probably would want

5____ Definitely would want

B. If **(PATIENT'S NAME)**'s heart stopped beating or s/he stopped breathing, would s/he want to receive cardiopulmonary resuscitation?

1____ Definitely would not want

2____ Probably would not want

3____ Unsure

4____ Probably would want

5____ Definitely would want

C. In this condition **(PATIENT'S NAME)** is unable to take in food or water by mouth, would s/he want artificial feeding and fluids?

1____ Definitely would not want

2____ Probably would not want

3____ Unsure

4____ Probably would want

5____ Definitely would want

Carer ID:

Date:

SCENARIO 3:

(PATIENT'S NAME) has advanced cancer which has spread to other areas. S/he is tired and weak, requiring some help with household chores. S/HE HAS PAIN THAT REQUIRES THE CONSTANT USE OF MEDICATION. In the opinion of his/her doctor, s/he has no chance of recovery. His/her doctor estimates that s/he has about six months to live.

A. If **(PATIENT'S NAME)** developed a serious infection, like pneumonia, would s/he want to use antibiotics to treat the infection?

1____ Definitely would not want

2____ Probably would not want

3____ Unsure

4____ Probably would want

5____ Definitely would want

B. If **(PATIENT'S NAME)**'s heart stopped beating or s/he stopped breathing, would s/he want to receive cardiopulmonary resuscitation?

1____ Definitely would not want

2____ Probably would not want

3____ Unsure

4____ Probably would want

5____ Definitely would want

C. If **(PATIENT'S NAME)** condition becomes such that s/he loses the ability to take in food or water by mouth, would s/he want artificial feeding and fluids?

1____ Definitely would not want

2____ Probably would not want

3____ Unsure

4____ Probably would want

5____ Definitely would want

SCENARIO 1:

Imagine you are in your current health, in other words, the way you are feeling now

SCENARIO 2:

Imagine you have suffered a severe stroke and have been in a coma for six weeks.

In the opinion of your doctor, you have NO CHANCE of regaining awareness or the ability to think, reason, and remember.

Your current physical condition is stable, but will slowly decline over time. You rely on others for help with feeding, bathing, dressing, and toileting. You may live in this condition for several years.

SCENARIO 3:

Imagine you have advanced cancer and it has spread to other areas. You are tired and weak, requiring some help with household chores.

IMAGINE YOU HAVE PAIN THAT REQUIRES THE CONSTANT USE OF MEDICATION. In the opinion of your doctor, you have no chance of recovery. Your doctor estimates that you have about six months to live.

Card A

1. **Antibiotics:**

Doctors use these medicines to treat serious infections (e.g., pneumonia). Without antibiotics, serious infections can cause life threatening complications or death.

2. **Cardiopulmonary Resuscitation (CPR):**

Doctors use cardiopulmonary resuscitation, or CPR, when a person's heart stops beating or a person stops breathing. Doctors press on the chest to help pump blood, and use artificial breathing. Artificial breathing means the doctor puts a tube in the windpipe. Then, a machine breathes for the patient through the tube.

Patients usually get medicines by vein. Patients often need an electrical shock to help restart the heartbeat. Without CPR, the heart will not start beating again, and the patient will die.

3. **Artificial Feeding and Fluids:**

Doctors use artificial feeding and fluids when people are unable to take enough food and water to stay alive. The food goes through a feeding tube. Usually, the feeding tube goes through the skin into the stomach. Without this treatment, patients die within 7-10 days.

Card B

- 1. I definitely would not want this treatment.**
- 2. I probably would not want this treatment.**
- 3. I am unsure if I would want this treatment.**
- 4. I probably would want this treatment.**
- 5. I definitely would want this treatment.**

Appendix 20: Ethics approval letter 12/LO/0106



Health Research Authority

NRES Committee South East Coast - Surrey

Room 12, 4th Floor West
Charing Cross Hospital,
Fulham Palace Road,
London
W6 8RF

Telephone: 020 3311 7283

31 January 2012

Dr Elizabeth Sampson
Honorary Consultant in Old Age Psychiatrist and Senior Lecturer in Psychiatric and supportive care of the elderly
UCL
Marie Curie Palliative Care Research Unit, 1st Floor, Charles Bell House
London
W1W 7EJ

Dear Dr Sampson

Study title: How well do people with dementia and their family carers agree on preferences for life sustaining treatment(s) at end of life and which factors influence these?
REC reference: 12/LO/0106
Protocol number: 11/0501

The Research Ethics Committee reviewed the above application at the meeting held on 17 January 2012.

Ethical opinion

Ethical issues raised and discussed by the committee in private discussion together with responses given by Miss Denning-Harrison when invited into the meeting. Members thanked Karen Denning Harrison for attending to discuss the study.

- i. The committee asked who would be conducting the interviews. Miss Denning-Harrison explained that she would be doing the interviews.
- ii. The committee asked how will Miss Denning-Harrison identify participants. Miss Denning-Harrison explained that they would come from the previous practices she has worked at and those who come to the clinic.
- iii. The committee asked for clarification on whether the capacity will be enough. Miss Denning-Harrison explained that there is a sufficient amount predicted to conduct the study.
- iv. The committee explained that the introduction to the PIS needed to be reworded. Miss Denning-Harrison took note.
- v. The committee asked for clarification of who will see the medical records of the participants, Miss Denning-Harrison explained that the staff will see the medical records but it will only be standard data and not the participant's medical history.

- vi. The committee explained that they felt that the scenarios needed to be reworded as it could cause anxiety to patients with dementia. Miss Denning-Harrison took note.
- vii. The committee explained that the medical information on the PIS is incorrect and needed to be accurate. Miss Denning-Harrison took note.
- viii. The committee wanted clarification on the inconsistency of the heading of Dementia and memory loss. Miss Denning-Harrison explained that this was the advice given to her and that it would be better that the disease was called memory loss. The committee felt that Dementia would be more appropriate. Miss Denning-Harrison took note.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Decision:

The Committee gave a favourable opinion of the application (with additional conditions)

Amendments requested

1. The committee felt that Dementia would be more appropriate name given to the disease rather than memory loss.
2. The introduction to the PIS need to be reworded

3. The scenarios need to be reworded as it could cause anxiety to patients with dementia
4. The medical information on the PIS needed to be correct.
5. In the PIS, the section under Study Aims the word 'access' should be changed to 'make decisions about'.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		23 December 2011
Evidence of insurance or indemnity		09 November 2011
GP/Consultant Information Sheets		23 December 2011
Investigator CV		16 November 2011
Letter from Sponsor		09 November 2011
Letter from Statistician	email exchange	18 November 2011
Other: CV for Karen Harrison Denning		23 December 2011
Participant Consent Form: Carers	2	23 December 2011
Participant Consent Form	2	23 December 2011
Participant Information Sheet	2	23 December 2011
Participant Information Sheet: Carers	2	23 December 2011
Protocol	1	12 December 2011
Questionnaire: included in the protocol		
REC application		20 December 2011
Referees or other scientific critique report	prof german berrios	19 November 2011
Referees or other scientific critique report	Lucy Whitman Ex carer	21 January 2011

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

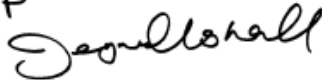
Further information is available at National Research Ethics Service website > After Review

12/LO/0106

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

PP


Prof David Russell-Jones
Chair

Email: georgina.marshall@imperial.nhs.uk

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*
"After ethical review – guidance for researchers" [SL-AR2]

Copy to: *Dr Dave Wilson*
Mr Thomas Mccauley, North Central London Research Consortium

Appendix 21: Modified LSPQ and carer variables - results

Table 1: Modified LSPQ and ZBI - Comparison of carer variables (n = 59)

Life Support Preference Questionnaire	No of dyads	Zarit Burden Interview				P	
		Mean	Mean difference	CI (95%)			
				Lower	Upper		
Scenario 1 'As you are today'							
1(a) antibiotics	Agree	54	28.1	-7.68	-21.09	5.71	0.25
	Disagree	5	35.8				
1(b) CPR	Agree	51	28.2	-4.32	-15.30	6.64	0.43
	Disagree	8	32.5				
1(c) Tube feed	Agree	43	28.8	0.103	-8.40	8.60	0.98
	Disagree	16	28.7				
Scenario 2 'Significant stroke and coma'							
2(a) antibiotics	Agree	32	26.3	-5.28	-12.73	2.16	0.16
	Disagree	27	31.6				
2(b) CPR	Agree	38	26.9	-5.32	-13.07	2.43	0.17
	Disagree	21	32.1				
2(c) Tube feed	Agree	39	29.0	0.70	-7.27	8.67	0.86
	Disagree	20	28.3				
Scenario 3 'Advanced cancer'							
3(a) antibiotics	Agree	31	29.3	1.24	-6.30	8.80	0.74
	Disagree	28	28.1				
3(b) CPR	Agree	40	29.3	1.74	-6.31	9.81	0.66
	Disagree	19	27.5				
3(c) Tube feed	Agree	39	28.1	-1.87	-9.83	6.08	0.63
	Disagree	20	30.0				

Notes: QCPR = Quality of care-giving relationship, CPR = Cardio Pulmonary Resuscitation, ZBI = Zarit Burden Interview

Table 2 Modified LSPQ and QCPR - Comparison of carer variables (n = 59)

Life Support Preference Questionnaire	QCPR		<P	
	Poor relationship (<56)	Good relationship (≥56)		
Scenario 1 'As you are today'				
1 (a) antibiotics	Agree	29	3	0.582
	Disagree	25	2	
1 (b) CPR	Agree	28	4	0.545
	Disagree	23	4	
1(c) Tube feed	Agree	20	12	0.047
	Disagree	23	4	
Scenario 2 'Severe stroke and coma'				
2 (a) antibiotics	Agree	16	16	0.327
	Disagree	16	11	
2 (b) CPR	Agree	18	14	0.124
	Disagree	20	7	
2(c) Tube feed	Agree	20	12	0.360
	Disagree	19	8	
Scenario 3 'Advanced cancer'				
3 (a) antibiotics	Agree	14	18	0.113
	Disagree	17	10	
3 (b) CPR	Agree	21	11	0.460
	Disagree	19	8	
3 (c) Tube feed	Agree	20	12	0.360
	Disagree	19	8	

Notes: QCPR = Quality of care-giving relationship, CPR: Cardio Pulmonary Resuscitation.

Table 3 Modified LSPQ and K(10) - Comparison of carer variables (n = 59)

Life Support Preference Questionnaire	Kessler Psychological Distress Scale			P	
	No of dyads	Mean	Z		
Scenario 1 'As you are today'					
1 (a) antibiotics	Agree	54	29.2	-1.22	0.22
	Disagree	5	39.0		
1 (b) CPR	Agree	51	30.2	-0.24	0.807
	Disagree	8	28.6		
1(c) Tube feed	Agree	43	29.8	-0.10	0.98
	Disagree	16	30.3		
Scenario 2 'Severe stroke and coma'					
2 (a) antibiotics	Agree	32	24.6	-2.60	0.009
	Disagree	27	36.3		
2 (b) CPR	Agree	38	28.2	-1.07	0.28
	Disagree	21	33.2		
2(c) Tube feed	Agree	39	31.4	-0.92	0.35
	Disagree	20	27.1		
Scenario 3 'Advanced cancer'					
3 (a) antibiotics	Agree	31	30.0	-0.3	0.97
	Disagree	28	29.9		
3 (b) CPR	Agree	40	31.1	-0.76	0.44
	Disagree	19	27.5		
3 (c) Tube feed	Agree	39	30.0	-0.03	0.97
	Disagree	20	29.9		

Notes: QCPR = Quality of care-giving relationship, CPR = Cardio Pulmonary Resuscitation, K(10) = Kessler Psychological Distress Scale

Appendix 22: Ethics approval letter for amendment to 12/LO/0106



NRES Committee South East Coast - Surrey

HRA
Bristol Research Ethics Committee Centre
Whitelands
Level 3, Block B
Lewins Mead
Bristol
BS1 2NT

Tel: 01173421331
Fax: 01173420445

30 October 2013

Dr Elizabeth Sampson
Honorary Consultant in Old Age Psychiatrist and Senior Lecturer in Psychiatric and
supportive care of the elderly
UCL
Marie Curie Palliative Care Research Unit, 1st Floor, Charles Bell House
London
W1W 7EJ

Dear Dr Sampson

Study title:	How well do people with dementia and their family carers agree on preferences for life sustaining treatment(s) at end of life and which factors influence these?
REC reference:	12/LO/0106
Protocol number:	11/0501
Amendment number:	Substantial Amendment 1, Sept 2013
Amendment date:	01 September 2013
IRAS project ID:	87251

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The Committee members approved the following changes:
Change to the protocol is the addition of three qualitative questions in a semi structured interview format.

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Participant Consent Form: Carer Consent Form	1	26 September 2013
Participant Information Sheet	1	26 September 2013
Notice of Substantial Amendment (non-CTIMPs)	Substantial Amendment 1, Sept 2013	01 September 2013
Participant Consent Form: Participant Consent Form	1	26 September 2013
Brief Interview Guide	1	26 September 2013

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All Investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

12/LO/0106:	Please quote this number on all correspondence
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Yours sincerely



Prof David Russell-Jones
Chair

E-mail: nrescommittee.secoast-surrey@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

Copy to: Mr Thomas Macaulay, North Central London Research Consortium
thomas.macaulay@nhs.net

Dr Dave Wilson
david.wilson@uclh.nhs.uk

MRs Harrison
karen.harrison-denning@dementiauk.org

NRES Committee South East Coast - Surrey

Attendance at Sub-Committee of the REC meeting

<i>Name</i>	<i>Profession</i>	<i>Capacity</i>
Dr JHP Powell	Consultant Physician / Committee Vice-Chair	Expert
Prof David Russell-Jones (Chair)	Professor of Diabetes and Endocrinology / Committee Chair	Expert

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Miss Gemma Oakes	REC Assistant

Brief Interview Guide (Version 1_26_Sept_2013)

Researcher starts by “thanking participants for taking part in the interview thus far; this final section will involve a few questions that are aimed at helping the researcher to understand how individuals and their families approach making important decisions”.

Researcher informs participant that the final section of the interview will be recorded to enable me to capture all that is said and that whatever is talked about (as with all the questions thus far) will be anonymised for the purposes of the study. The recordings will be deleted once transcribed. The participant will be reminded that if they can stop the interview at any time or leave the room and to please tell me.

We have talked about decisions relating to various treatments in various potential ill health situations; in the last part of my interview I would like to ask you a few questions about how you make decisions within your family. Over time, families develop their own particular approaches and processes for making decisions, especially significant decisions; examples of such significant decisions might be buying a house, starting a family etc. I would like to understand how you and your (family member) have made decisions in the past:

- 1. How have important decisions been made in your family in the past?**

- 2. What changes to this decision making process (if any) do you see the diagnosis of dementia has made?**

- 3. What decisions do you think need to be made in the future now that there is a diagnosis of dementia made (for you/your family member)?**

- 4.**

Is there anything you would like to add or comment on?

Thank you for taking part in my study.

Appendix 24: Participant information sheet, nested qualitative interviews



Barnet, Enfield and Haringey
Mental Health NHS Trust



Participant Information Sheet
(Version_4_Aug_2013)

Karen Harrison Dening
Head of Nursing, Admiral Nursing
Dementia UK
6 Camden High Street
London NW1 0JH

Tel: 020 7874 7200
Email: karen.harrison-dening@dementiauk.org

Study Title: How well do people with dementia and memory problems and their family carers agree on preferences for life sustaining treatment(s) at end of life and which factors influence this?

(Student PhD Project)

Additional questions

My name is Karen Harrison Dening and I am an Admiral Nurse (specialist nurse working with families affected by dementia) and am undertaking PhD studies at University College London. You recently took part in an interview for my research. This second information sheet supplements the first one I gave you. I would like to invite you to agree to a further brief interview. I will contact you after seven days to see if you want to take part. Please let me know if you need longer.

What will the brief interview involve?

I would like to interview each patient and their carer again, this can either be in a private room within the hospital or clinic or within your own home, you can choose. I will ask you some questions about how you have made healthcare decisions in the past; this part of the interview will be audio recorded so I can capture all that is said. The recording will then be transcribed and all recordings then destroyed.

Will my taking part in the study be kept confidential?

Yes. All information collected about you during the course of the research will be kept strictly confidential. Any information about you will have all identifiable information removed so that you cannot be recognised from it. This anonymous information will be collected, stored handled and processed by the researcher at University College London. Our procedures for handling, processing, storage and destruction of data are compliant with the Data Protection Act 1998.

What will happen if I don't want to carry on with the study?

That is fine, just let the researcher know and they will stop the interview and the recording. If you do not want me to use the information you have given me, just let

me know and it will be destroyed. This will not affect any future care you may receive.

Karen Harrison Dening
Head of Nursing, Admiral Nursing
Dementia UK, 020 7874 7200

Appendix 25: Participant consent form, nested semi-structured interviews



Barnet, Enfield and Haringey 
Mental Health NHS Trust



Participant Consent Form

(Version_1_26_Sept_2013)

Karen Harrison Dening
Director of Admiral Nursing
Dementia UK
Second floor
Resource for London
356 Holloway Road
London
N7 6PA

T 020 7697 4183 F 020 7697 4051

Email: karen.harrison-dening@dementiauk.org

Participant Identification Number:

Name of Principal investigator: Karen Harrison Dening

Title of project: How well do people with dementia and memory problems and their family carers agree on preferences for life sustaining treatment(s) at end of life and which factors influence this?

(Student PhD)

Additional short interview.

Please initial box

- 1 I confirm that I have read and understood the information sheet (version_1_Sept_2013) for the above study and have had the opportunity to ask questions.
- 2 I confirm that I have had sufficient time to consider whether or not I want to be included in this additional brief interview.
- 3 I confirm that I agree to the digital recording of the interview and understand that this recording will be deleted once the interview is transcribed.
- 4 I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my care or legal rights being affected.
- 5 I can choose to be interviewed in my own home if I wish.
- 6 I agree to take part in the added, short interview to the main study.

This form continues onto a second page.

CONSENT FORM continued

Participant Identification Number:

Title of project: How well do people with dementia and memory problems and their family carers agree on preferences for life sustaining treatment(s) at end of life and which factors influence this?
(Student PhD)

Additional short interview.

_____	_____	_____
Name of participant	Date	Signature
_____	_____	_____
Researcher	Date	Signature

1 form for participant

1 to be kept as part of the study documentation

1 to be kept with hospital notes

Appendix 26: Carer Consent form, nested semi-structured interviews



Barnet, Enfield and Haringey
Mental Health NHS Trust



Carer Consent Form

(Version_1_26_Sept_2013)

Karen Harrison Dening
Director of Admiral Nursing

Dementia UK

Second floor

Resource for London

356 Holloway Road

London

N7 6PA

T 020 7697 4183 F 020 7697 4051

Email: karen.harrison-dening@dementiauk.org

Participant Identification Number:

Name of Principal investigator: Karen Harrison Dening

Title of project: How well do people with dementia and memory problems and their family carers agree on preferences for life sustaining treatment(s) at end of life and which factors influence this?

(Student PhD)

Additional short interview.

Please initial box

1. I confirm that I have read and understood the information sheet (version_3_Feb_2012) for the above study and have had the opportunity to ask questions.
2. I confirm that I have had sufficient time to consider whether or not I want to be included in this additional brief interview.
3. I confirm that I agree to the digital recording of the interview and understand that this recording will be deleted once the interview is transcribed.
4. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my care or legal rights being affected.

This form continues onto a second page

CONSENT FORM continued

Participant Identification Number:

Title of project: How well do people with dementia and memory problems and their family carers agree on preferences for life sustaining treatment(s) at end of life and which factors influence this?

(Student PhD)

Additional short interview.

_____	_____	_____
Name of participant	Date	Signature
_____	_____	_____
Researcher	Date	Signature

1 form for participant

1 to be kept as part of the study documentation