A study to explore influences on acceptance and rejection of psychosocial interventions by people with early dementia

by

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Publications and presentations

Publications

Field, B Mountain, G et al (2019) Recruiting hard to reach populations to studies: breaking the silence. An example from a study that recruited people with dementia. *BMJ Open* 2019;9:e030829. doi:10.1136/bmjopen-2019-030829

Field, B Coates, E and Mountain, G (2019) 'Influences on uptake of a community occupational therapy intervention for people with dementia and their family carers', *British Journal of Occupational Therapy*.82(1):38–47doi:10.1177/0308022618804479.

Hynes, SM **Field, B** et al (2016) Exploring the need for a new UK occupational therapy intervention for people with dementia and family carers: Community Occupational Therapy in Dementia (COTiD). A focus group study. *Aging & Mental Health* 20(7):762-769

Oral presentations

Local, national and international academic conferences

Field, B (July 2019) *Psychosocial interventions for people following a dementia diagnosis: identifying what influences acceptance or rejection* Dementia Futures Conference, University of Sheffield, Sheffield.

Field, B (May 2019) *Psychosocial interventions for people following a dementia diagnosis: identifying what influences people to agree or refuse service offers* Alzheimer's Society Conference, London.

Field, B (June 2017) *Identifying influences on take up of a community occupational therapy intervention for people with dementia and family carers* Royal College of Occupational Therapists Conference, Birmingham.

Field, B (November 2016) *Psychosocial interventions after diagnosis: identifying influences on take up* Alzheimer's Europe Conference**,** Copenhagen.

Field, B (May 2016) *Psychosocial interventions for people living with dementia: identifying influences on take up* Post-Graduate Research Conference, ScHARR, University of Sheffield, Sheffield.

Other presentations

Field, B (September 2019) *Support and activities for people with early dementia: identifying what influences acceptance or rejection* Sheffield City Council 'People Keeping Well Link Workers' event, Sheffield.

Field, B (March 2019) *Psychosocial interventions for people with early dementia: identifying influences on uptake. Initial findings for Occupational Therapists to consider* Specialist Section Older People-Dementia Clinical Forum Study and Networking Day, Royal College of Occupational Therapists, London.

Field, B (November 2017) *Identifying influences on take up of a community occupational therapy intervention for people with dementia and family carers* Occupational Therapy Forum, Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield.

Academic Posters

Field, B (June 2019) *Interventions Occupational Therapists offer people with dementia after diagnosis: influences on uptake* Royal College of Occupational Therapists Conference, Birmingham.

Field, B (May 2015) *Psychosocial interventions for people living with mild to moderate dementia in the community after diagnosis: can 'readiness to engage' be identified?* Post-Graduate Research Conference, ScHARR, University of Sheffield.

Awards and recognition

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Declaration

I, the author, Becky Field, confirm that the Thesis is my own work. I am aware of the University's Guidance on the Use of Unfair Means (www.sheffield.ac.uk/ssid/unfair-means). This work has not been previously been presented for an award at this, or any other, university.

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Abbreviations used in this thesis

AD Alzheimer's Disease

CDR Clinical Dementia Rating Scale

CST Cognitive stimulation therapy

CBT Cognitive behavioural therapy

FTD Frontal temporal dementia

JDR Join Dementia Research

LGBTQ+ Lesbian Gay Bisexual Transgender and Queer+

MMSE Mini Mental State Examination

MSNAP Memory Services National Accreditation Programme

NHS National Health Service

NICE National Institute for Health and Care Excellence

NIHR National Institute for Health Research

OT/OTs Occupational Therapist/s

PIS Participant information sheet

RCT Randomised control trial

RCOT Royal College of Occupational Therapists

UKOTRF UK Occupational Therapy Research Foundation

VALID Valuing Active Life in Dementia research programme

VD Vascular Dementia

Abstract

Background

Health policy promotes post-diagnostic support for people affected by dementia. Evidence suggests psychosocial interventions can support people with dementia. Yet what influences people with dementia accept interventions is poorly understood. This research aimed to identify influences on acceptance or rejection of psychosocial interventions by people with early dementia.

Methods

Sixteen face-to-face semi-structured interviews with people with early dementia (either alone or with a family member/s). Twelve staff participate in semi-structured interviews or a focus group.

Thematic analysis and triangulation enabled integration of findings and identification of themes across all data sources. Findings, along with key themes from literature reviewed, informed a summary framework of influences on acceptance and rejection of psychosocial interventions by people with early dementia.

Main Findings

Five overarching themes were identified. Individual responses to diagnosis, experiences of dementia and dementia services influenced uptake. Adjustment and awareness affected whether people felt they needed interventions. Whether activities offered appealed and benefit was influenced uptake. Interventions offering social contact, peer support, information, enjoyable activities and mental stimulation were valued. Group interventions or interventions specifically aimed at people with dementia did not appeal to all. Continuing with community activities was valued. Ability to travel and convenience of locations was important Stigma seemed to discourage uptake. Emotional and practical support from family was key to facilitating uptake and relationships between people affected by dementia and staff were also important.

Conclusion

A complex interplay of individual, service and societal influences affect uptake of psychosocial interventions by people with early dementia. How interventions, and which services, should enable people with early dementia remain engaged in their everyday lives needs consideration. Further research to examine acceptance and rejection of specific interventions commonly offered to those with early dementia is needed. Involving people with early dementia in the design of interventions aiming to support them is paramount.

Chapter 1 Introduction

1.1 Importance of this research

Dementia is a global health problem, affecting individuals, society and the economy. There are an estimated 50 million people with dementia worldwide with projections for over 100 million affected people by 2050 (1). Dementia is one of the major causes of disability and dependency among older people worldwide. Approximately 850,000 people live with dementia in the UK, likely to increase to over one million by 2022 (2). The financial cost to the NHS, local authorities and families is estimated at over £26 billion per year (2). In the absence of a cure, interventions to support people to live well with dementia and remain in the community for as long as possible are imperative.

In England, NHS memory services have been established to provide expert advice and facilitate timely diagnosis (3,4). Subsequently diagnosis rates have increased (5). The need to then support people with dementia and their families after diagnosis has been increasingly recognised nationally and internationally (6–11).

A growing evidence base indicates that psychosocial interventions can offer support to people with dementia and their families after diagnosis (12–15). Research into psychosocial interventions has reported benefits such as maintaining or improving cognition (16–18), maintaining or improving independence with daily tasks and carer competence (19) and achievement of personal goals (20). Some research has also suggested that benefits offered by some psychosocial interventions may equal or enhance the effects offered by pharmacological interventions (16,21).

However, there appears to be little research about what influences people with dementia accept or reject offers of psychosocial interventions. This study aimed to address this research gap.

1.2 How my interest in this topic developed

My interest in this topic began through my involvement in a research programme funded by the National Institute for Health Research, called 'Valuing Active Life in Dementia' (VALID) (22). VALID evaluated the clinical and cost effectiveness of one psychosocial intervention - community occupational therapy - designed to promote independence and meaningful activity by the person with dementia and their family member. I was responsible for recruiting people with dementia and family members as research participants. When trying to recruit

people and promote the intervention I found that whilst some people were keen to accept the offer, many others declined. For example, some people with dementia were unsure the intervention was for them, stating that it was 'too early' for them or they did not have any major difficulties. I also found that some clinical staff, although fully briefed did not refer potentially suitable people. Such issues led me to question why people with dementia and their families may accept or reject offers of interventions designed to support them and the need to explore further whether what is offered after diagnosis was meeting people's needs. My interest in these issues led me to authoring a publication (23) (Appendix 1.1) which reflected upon why recruiting people with dementia to research studies can be challenging.

When the opportunity to complete a PhD associated with and part funded by the VALID programme arose, I discussed ideas with my first supervisor and we drafted a proposal. I presented this proposal to the VALID Chief Investigator and VALID Project Management Group and this was accepted. I registered for a part-time PhD at ScHARR as a staff candidate in October 2014.

1.3 Dementia policy drivers

Dementia is a key priority for NHS England and the Government. In 2009 a National dementia strategy was published (9). In 2012, the Prime Minister launched the 'Prime Minister's Challenge on Dementia' (6), with one goal being timely diagnosis. Following increased rates of diagnosis, a subsequent Prime Minister's Challenge was launched, followed by an implementation plan (5,7). These documents included a focus on improving post-diagnostic support and stated that every person diagnosed with dementia should have meaningful care following diagnosis. The importance of post-diagnostic support is also highlighted by the Memory Services National Accreditation Programme (MSNAP) (10), which recommends that memory services should offer a range of different psychosocial interventions after diagnosis.

The importance placed on post-diagnostic support is further highlighted by NHS England's 'Well Pathway for Dementia' (11). This document refers to 'preventing well', 'living well', 'supporting well' and 'dying well'. It includes guidance for commissioners and providers about ensuring people with dementia get timely access to post-diagnostic support and treatment. The 'living well' and 'supporting well' aspects of this document recognise that whilst people continue to live in the community after a diagnosis, enabling them and their families to live as well as possible with the condition, be able to participate socially and maintain quality of life are important. The National Institute for Health and Care Excellence (NICE) evidence based guidelines for dementia services and commissioners explicitly

recommend one psychosocial intervention for people with mild to moderate dementia (group Cognitive Stimulation Therapy (CST) (24). These guidelines also suggest that services consider offering other psychosocial interventions, such as group reminiscence therapy, cognitive rehabilitation or occupational therapy and a range of activities to promote wellbeing tailored to a person's preferences (24).

1.4 Involvement of people with dementia in research

Until the 1990s the perspectives of people with dementia were mostly ignored within dementia research (25). This was partly due to concerns about ability to consent and participate in research and that testimonies of people with dementia were unreliable. Previously, researchers often used accounts of the experience of dementia based on family carer reports. Whilst such accounts gave useful insights, researchers also started to find that proxy accounts differed from those obtained from by people with themselves (for example (26,27)). It became clear that if the experience of living with dementia was to be understood, including people with dementia as research participants was necessary. Also, now that people are diagnosed earlier they are more likely to be able to participate in research studies to represent their own perspectives and experiences of living with dementia. It is now recognised that people with dementia themselves can act as research participants and express their own views when supported to do so (for example, (25,28,29)). More recently, the ways in which people with dementia have been involved in research has developed and been questioned, to include people living with dementia not only as research participants but also advisors or co-researchers within research studies (30–32). A research priority setting consultation exercise completed by the Alzheimer's Society and the James Lind Alliance included people with dementia as stakeholders alongside family carers and professionals (33). This exercise identified 10 research priorities. The majority of these focused on supporting people to live with dementia, as opposed to seeking a cure. One of the questions identified was *'What are the most effective components of care that keep a person with dementia as independent as they can be at all stages of the disease in all care settings?'* As psychosocial interventions can support people with dementia to live as well as possible after diagnosis, I regard this PhD study as contributing to this field of 'care' focused research by starting to address the evidence gap about what influences people with dementia accept or reject offers of psychosocial interventions, whilst seeking to represent the perspectives of people with dementia themselves as research participants.

1.5 The focus of this thesis and preliminary research

The focus of this thesis is primary research I conducted, as well as the findings from a scoping literature review and a review of current evidence about psychosocial interventions. Empirical findings and the literature identified have been used to identify influences on acceptance and rejection of psychosocial interventions by people with early dementia. However, this research has involved two phases. Phase 1 (2014-16) involved preliminary work to help clarify research questions and methods for a main study (phase 2, 2016-2020). The preliminary work included a scoping literature review and a secondary analysis of existing qualitative interviews with research participants from the VALID research programme, conducted during the intervention development phase of that programme.

Seventeen interviews were completed with participants (people with dementia and family members, interviewed as a pair) who had completed the occupational therapy intervention together as part of the VALID research programme. The primary aim of these interviews had been to explore intervention acceptability and how it might need adapting for future use. I conducted a secondary qualitative analysis of these interviews to explore whether I could identify any data about influences on uptake of this intervention. I had conducted three of the joint interviews myself and the other interviews were conducted by other research staff working on the VALID programme. Describing all aspects of this preliminary work within the word count required for this thesis was not possible. However, this work and the findings from the secondary analysis of interviews are presented in a first author peer reviewed publication (34) (Appendix 1.2).

The main findings of that secondary analysis can be summarised as follows: Four main themes and two subthemes were identified. The first main theme was about how uptake was influenced by the impact of dementia on people with dementia and family members who wanted support to adjust or cope with living with dementia. Within this, a subtheme was identified about the timing of the intervention offer being important to uptake. The second main theme concerned whether people were looking for new activities or they felt they had enough activities to do. A subtheme identified that previous experiences of other interventions may have influenced uptake of this intervention. The third main theme was about limited initial expectations people appeared to have about the intervention they had been offered and accepted. The final main theme was about positive attitudes towards trying the intervention, even though some people with dementia and family members felt uncertain or worried about participation. One particular limitation to this work had been that family member accounts dominated most of the joint interviews and I was uncertain about how

people with dementia had been supported to express themselves within the joint interviews. I concluded that this secondary analysis had identified some preliminary ideas about influences on uptake of that specific occupational therapy intervention, offered as part of the VALID programme. I also concluded there was a need for primary research to examine why people with dementia and family members may or may not be ready to engage with interventions offered by services that aimed to contribute to and improve their quality of life.

Therefore, this preliminary work assisted with the creation of the research questions and the methods for the primary research I conducted for the main study as well as informing the preliminary model of readiness to engage suggested in Chapter 2.

1.6 Research aim, objectives and research questions

The aim of the main study was to identify influences on acceptance or rejection of psychosocial interventions by people living in the community with early dementia. The objectives and research questions are now presented.

Research objectives

1.   To develop understanding of influences on people with dementia that may affect acceptance or rejection of psychosocial interventions.
2.   To identify whether and how staff account for people with dementia's acceptance or rejection of psychosocial interventions.
3.   To propose a model of 'readiness to engage in psychosocial interventions'.
4.   To identify implications for practice, policy and further research.

Research questions

1. What do people with dementia report about interventions they have been offered (when they are interviewed alone or jointly with a family member)?
      1.1 What are their views about what is offered?
      1.2 What else do they consider could be offered to meet their needs?

2. What do family members report about interventions the person with dementia they support or, they as a dyad, have been offered (when interviewed jointly with a person with dementia)?
      2.1 What are their views about what is offered?
      2.2 What else do they consider could be offered to meet both their needs?

3. What do staff report about the uptake or rejection of interventions?
      3.1 Who offers interventions, in what context and when?

3.2 How do staff describe responses to intervention offers?

3.3 Do staff identify unmet needs for people recently diagnosed with dementia? If so, how do they think they should be met?

4. What appears to influence people with a dementia to accept or decline interventions?

5. What implications are there for policy, practice and research?

1. 7 Definitions of key terms and concepts used in this thesis

1.7.1 Dementia

In this thesis I use the term 'dementia' as an umbrella term to mean any type of dementia a person may be diagnosed with, of which there are many different types. In the UK, Alzheimer's Disease is the most common, followed by vascular dementia, frontal-temporal dementia, mixed dementia or Lewy bodies dementia and other less common forms (2).

The World Health Organisation defines dementia as
> *'…a syndrome, usually of a chronic or progressive nature in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement…the impairment in cognitive function is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation…..'*
> (35).

NICE recommend pharmacological treatment for those diagnosed with mild to moderate Alzheimer's Disease which can involve prescription of acetyl cholinesterase inhibitors (24) and give guidance on pharmacological treatment and its contraindications for other types of dementia. Such treatments may temporarily reduce some symptoms experienced for some people (24) .

People living with dementia find it increasingly difficult to remember, know where they are, who other people are, keep track of time, organise themselves, understand and communicate, make decisions or learn new information. Given this, people often experience difficulties with carrying out every day activities and continuing with the roles they value (36). Family members can also feel an increased sense of stress or burden as they try to cope with these challenges (37). Also, most people with dementia experience impairment over and above that stemming from neurological impairment and biological factors (38). The definition of dementia given above as a syndrome is limited and informed by a biomedical approach which understands dementia as a disease of three stages, early, middle and late

(39). Biomedical approaches assume causal relationships between the pathology of the brain and the condition of dementia (40). However, a biopsychosocial model of dementia highlights the importance of factors additional to, and interacting with, biological or neurological factors (38,41). Whilst dementia is a degenerative disease that involves a progressive decline in people's functioning, performance and behaviour are also influenced by mood, health state, motivation and environment. Psychological factors such as denial, adjustment, depression or anxiety and societal factors such as stigma, social isolation or social support and economic resources all influence the lived experience of dementia (38,42). It is also important to consider a person-centred understanding of dementia, first presented by Kitwood (41). Although this work focused on people with dementia living in residential care settings it highlighted the central importance of an individual's own experience of living with dementia and the social and physical environmental influences on an individual's experiences of dementia and abilities. More recently understanding of dementia from a person-centred perspective has developed. Vernooij-Dassen and Moniz-Cook (43) argue the importance of recognising that people with dementia and family care givers are experts on their lived experience, in which they overcome some of the challenges presented by dementia, that people with dementia can remain active, engaged with life, contribute and maintain their identify, whether living in their own homes or care settings.

So whilst I understand the term dementia to mean a 'syndrome', with a degenerative, neurological disease process occurring, I also understand it as an individual experience greatly influenced by psychosocial factors. Thus I work within a biopsychosocial model (38) and person-centred understanding of dementia (43).

A further consequence of dementia is the impact on family members, who can feel an increased sense of stress as they try to cope with the challenges presented by dementia. Yet it has also been recognised that the way in which family members support a person with dementia can optimise or decrease the person's abilities and influence the degree of disability, lack of agency or sense of control experienced (36,41).

1.7.2. 'Early' dementia

I have chosen to use the term 'early' dementia, together with 'living in the community' to clarify the focus of this research and my study population. The health research, policy and practice literature uses a variety of terms to describe this population. For example, 'mild to moderate dementia' 'early-stage' 'early' or 'post-diagnosis' are all used, sometimes interchangeably. These terms may not always be defined or the definition varies (14).

I felt using the term 'early' dementia was suitable for a psychosocial understanding of dementia which recognises the individual experience of dementia and that people with dementia may function more or less well at different times. I hoped this would encompass those whose cognitive difficulties and lived experience of dementia were such that they may be able to benefit from psychosocial interventions offered to people following diagnosis living in the community. Also I considered the term 'early dementia' would be terminology understood by the people with dementia, family and staff that I wanted to recruit as participants. However, much of the research literature does use the term mild-to-moderate dementia and in clinical practice or research studies, standardised assessments are often used to define a stage of dementia. Therefore when referring to published studies which have used those terms I refer to mild-to-moderate dementia.

1.7.3 The concept of social health and dementia

The concept of social health applied to dementia (44) recognises that understanding the pathology and negative consequences of dementia is necessary to finding a cure or ways to compensate for challenges. Yet, the concept of social health and dementia also proposes it is imperative to understand the remaining capacity individuals with dementia may have. Vernooij-Dassen et al (44) suggest that not acknowledging the potential of individuals can create an additional threat to their capacity to lead a quality life. They contend that three decades of psychosocial research on dementia have shown the importance of social engagement, environmental support and working with the residual capabilities of the person with dementia (44). The concept of social health challenges common beliefs that the capabilities of people with dementia cannot be maintained or be improved. The model of social health proposes that seeing the person with dementia from the perspective of social health helps to focus on the person's needs (such as love, comfort, attachment, involvement, identity and meaningful occupation) and their positive and negative experiences. I consider that psychosocial interventions for people are one way in which the social health of people with dementia can be supported. This is because psychosocial interventions for people with early dementia require recognition of the remaining capacity that individuals with dementia, may have and of their strengths and abilities, as well as the challenges they are faced with.

1.7.4 Stigma

Goffman (45) conceptualised stigma as 'spoiled identity'. Link and Phelan (46) described stigma as people being negatively labelled, a loss of status and power, discrimination and stereotyping. There is often a lack of awareness and understanding of dementia, resulting in stigmatisation and barriers to diagnosis and care (35). Existing research has highlighted

how stigma may act as a barrier or cause reluctance to use services by people with dementia. For example, Swaffer (47), who lives with young onset dementia, describes how stigma affects people with dementia's willingness to seek diagnosis and then to seek support once diagnosed. From a psychological perspective, Sabat's work (48) acknowledges the importance of others, and thus also stigma, in the construction of 'self' in people with dementia. Sabat (48) suggests there are three possible constructions of the self for people are living with dementia. In 'Self 1' the use of pronouns indicates the responsibility people take for their actions, feelings and experiences and this self generally remains intact in dementia. In 'Self 2' mental and physical attributes and personal beliefs about these attributes are important, people may take pride in such attributes as 'having a good memory' or 'being the organiser' but experiencing dementia symptoms may change this sense of 'Self 2'. In 'Self 3', people with dementia may construct different social personalities, fulfilling different social roles. This 'Self 3' may be threatened if visible symptoms of dementia lead others to discredit the person with dementia by questioning their personal attributes and stigmatising their behaviours. More recently, Sabat (49) also argued that the dominance of a biomedical approach for dementia contributes to stigma. For example, the diagnostic assessment process, whereby people are 'tested' to identify cognitive deficits and when that experience is a sense of 'failure', this contributes to stigma and spoiled identify.

Swaffer (50) coined the term 'prescribed disengagement' to explain post-diagnostic advice often given by health professionals. This advice either explicitly or implicitly suggests that the person should be slowing down or pulling back from activities. Swaffer (50) explains how such 'prescribed disengagement' increases the stigma and discrimination people with dementia experience. This may imply a reluctance to engage with services or interventions that require engagement and activity. A systematic literature review (51) concluded although there was not support for the idea of 'prescribed disengagement' within the literature examined, there was much evidence of isolation, loss of hope, self-esteem, self-identity, threats to social health and stigma. As such the diagnosis process and post-diagnostic support may contribute to disempowering people with dementia, exacerbating negative views and self-stigma (51).

Stigma has also been found to be one of several barriers to use of dementia services by minority ethnic groups (52,53). Feelings of stigma and shame were found to be associated with dementia by in three different ethnic minority groups in England (52). Minority ethnic groups presenting later to dementia services and experiences of stigma within communities have also been reported, along with other reasons, as a main barrier to help seeking for

dementia. Older people with dementia also have to overcome the double stigma of age and dementia (42).

Moniz-Cook and Manthorpe (42) describe stigma as resting on the belief that there is little to offer people with dementia, since it is a deteriorating disease and this leads a pessimism in prognosis, which in turn leads to 'rehabilitative nihilism' (p.17). Yet, as Moniz-Cook and Manthorpe (42) suggest, psychosocial interventions aiming to strengthen personal and social identities for people recently diagnosed with early dementia can help address stigma.

1.7.5 Psychosocial interventions

There does not appear to be one accepted definition of psychosocial interventions; rather it is used as an umbrella term encompassing many different kinds of non-pharmacological interventions that may be offered to people with dementia and their family members, either alone or together. Such interventions can differ greatly in content, target outcomes (for example, quality of life, cognitive function, independence, carer coping), length and modes of delivery (for example, group work, working with the person with dementia and family member together or with the person with dementia or family member separately) (13,14). However interventions aimed at family members alone are outside the scope of this research.

For this research and thesis I use the following broad definition of psychosocial interventions from Moniz-Cook et al (54):

> *"….interventions involving interaction between people to improve psychological and/ or social functioning, including well-being and cognition, interpersonal relationships and everyday functional abilities, such as activities and daily living skills."*
> (p.45)

I also interpret this to mean psychosocial interventions are activities offered by professionals, working in health or other services, to people with early dementia. Further, I note that Moniz-Cook and Manthorpe (42) describe psychosocial interventions as including signposting and more active interventions aiming to address well-being by addressing cognitive, psychological or social factors. Signposting can mean informing people with dementia and family members about other services that may offer support rather than more active intervention. Thus I include signposting as a type of psychosocial intervention in my definition of psychosocial interventions. I chose to use this broad, inclusive definition of psychosocial interventions because I did not want to make assumptions about the types of interventions people with dementia and family members and staff would discuss in the interviews. I wanted to approach this with an open mind in order to explore and find out which interventions they would describe.

However, the concept of 'interventions' being offered by health or other services to support those affected by dementia can perhaps be questioned. Illich (55) many years ago wrote about how modern medicine aimed to eradicate pain, sickness and even death. Yet, Illich (55) argued, these aspects of life were eternal realities with which people must learn to cope and that coping with such challenges was part of what it meant to be 'healthy'(56). Illich referred to 'iatrogenesis' (meaning the harm done by doctors) and the phrase 'social iatrogenesis' to describe what he saw as the medicalisation of ordinary life (56). These ideas have some resonance when considering the concept of psychosocial interventions as one way that health or other services aim to support those affected by dementia. I regard psychosocial interventions as trying to support people with dementia to live with the challenges that life with dementia may present, aiming to enable those affected by dementia to live as well as possible and cope, utilising their strengths and resources, rather than encouraging an over reliance on pharmacological or medical intervention. Perhaps the term 'intervention' itself could be considered to contribute to a medicalisation of dementia which might not be helpful to people living with the condition. I recognise the need to avoid medical jargon and terminology for this reason. I also consider that the term psychosocial intervention may have arisen from the need to define and highlight alternative approaches to pharmacological treatments in a positive way rather than for example, defining these approaches by what they are not, for example, the term 'non-pharmacological' interventions.

Whilst I recognised the importance of defining the term 'psychosocial interventions' for this research and thesis, I also recognise that 'psychosocial intervention' as a term could be considered health care or medical jargon. I felt it was unlikely to be used or understood people with dementia and family members that I would aim to recruit. Guidance from the Dementia Empowerment and Engagement Project (DEEP) (57) advises against using jargon, which 'psychosocial intervention' or 'intervention' could be regarded as. Therefore, I used the terms 'support and services' in all participant materials, in place of the term 'psychosocial interventions' as I was concerned that people with dementia and family members would not understand or use the term 'psychosocial interventions'. I consulted the South Yorkshire Dementia Research Advisory group (a patient and public involvement group of family members and people with dementia) about participant materials for this PhD research. They advised using plain language and avoiding complicated words, their view was that the participant materials for this PhD research were appropriate, clear and understandable. However, whilst I used the term 'support and services' in participant materials I decided to use the term 'psychosocial interventions' within the reporting of this research and thesis. This is because I felt it may be a helpful way to refer to the variety of interventions likely to be discussed by participants, in language familiar to my intended audience (i.e. practitioners

and researchers). My experience when working with practitioners in dementia services during the VALID study (section 1.2) was that they used the term 'psychosocial interventions' when talking to me about post-diagnosis support and this terminology was also commonly used within the research literature I had examined when beginning this research.

1.7.6 Readiness to engage

My third research objective (Section 1.6 above) was to 'propose a model of readiness to engage in psychosocial interventions'. This was intended as a way to present the new knowledge gained about what influences uptake of interventions by people with early dementia and feel ready to engage with an intervention, presenting in a format that may be helpful to practitioners and researchers in the field.

At the outset of this research I was unsure whether interventions described by participants during interviews would be interventions with intended behaviour change outcomes, or if I would be able to make this judgement from the way participants described interventions. This was because of the variety of interventions reported within the research literature (for example (12,13,16,18) and my own knowledge of interventions commonly offered in practice, which suggested that not all psychosocial interventions are focused explicitly on behaviour change as a potential outcome. For example, my previous research experience (see Section 1.2 above) indicated that memory services in England often offered cognitive stimulation therapy groups (CST) which primarily aim to improve or maintain cognition and facilitate social interaction. Whereas, other non-NHS organisations may offer activity groups aiming to promote social interaction, enjoyment, reduce isolation and support well-being and quality of life but may not have defined, measurable outcomes (for example memory cafes run by the Alzheimer's Society). As outlined in Section 1.7.5 above, I had intentionally selected a broad and inclusive definition of psychosocial interventions. My interpretation and understanding of that definition was that the psychosocial interventions encompassed by such a definition could involve interventions aiming to facilitate individual intentional behaviour change but also may not.

Also as an occupational therapist (see Chapter 3 section 3.2.2) I had long questioned what led people to engage with brain injury rehabilitation programmes, which required behaviour change to learn and use strategies. This clinical experience suggested readiness to engage in rehabilitation programmes was complex; each person's personality, the area of the brain injured, circumstances of their injury, socioeconomic situation and emotional state well as cognitive abilities and awareness of their difficulties had all seemed important to engagement and acceptance of interventions.

I was unsure whether using existing theories or models of behaviour change could help guide this research and help identify the process of change, in relation to uptake and readiness to engage with psychosocial interventions. Further, the focus of this research was more upon the beginning of a change process i.e. an acceptance or rejection of an initial intervention offer and an initial willingness, to engage with an intervention, rather than process of engaging with an intervention over time or the attainment of a measurable behaviour change outcome. However, I did consider whether existing theories or models or frameworks could offer ways to conceptualise the process of change over time or engagement with interventions initially.

The 'transtheoretical model' of change (58) is based on an examination of how people with addictive behaviours change, either with or without professional support. This theory proposes that there is a behaviour change cycle, involving different stages of change: 'precontemplation', 'contemplation', 'preparation', 'action' and 'maintenance'. These stages are cyclical, people may go through them several times, rather than change involving a neat linear progression towards maintenance of change. I considered applying the transtheoretical model (58) to guide my study design (i.e. the research objectives, research questions, questions to during interviews, a priori codes for analysis and therefore eventually to inform the model of readiness to engage I aimed to propose). The stages of change appealed as way to conceptualise how people may move from not being ready to change to a readiness to change but I was unsure about the 'fit' for examining uptake of psychosocial interventions by people with early dementia. Firstly, the transtheoretical model theory is deliberately focused on the phenomenon of individual, intentional change (58), as opposed to including for example, societal change or influences. Given that the psychosocial model of dementia, to which I subscribe, emphasises social and contextual issues affecting the experience, behaviour and abilities of a person with dementia I was unsure if applying this theory was appropriate. This is because dementia is a condition which, along with psychosocial aspects has an neurological, degenerative disease process taking place. This affects people's abilities to think and reason and thus I questioned if using a theory with an explicit focus on individual intentional behaviour change may not facilitate recognition of other psychosocial factors that may affect readiness to engage in an intervention for an individual with early dementia.

Berg (59) suggests there are three main 'types' of people who may attend psychological therapy: the 'visitor', who attends often at the request of another or others, but who themselves is not invested in change; the 'complainant' who is aware of difficulties but does

yet see how their own behaviour could alleviate the difficulties; the 'customer' who is essentially a therapist's 'ideal' type as they are ready and willing to solve the problem working with a therapist. Berg (59) suggests therapists respond to these different types accordingly, such as not suggesting tasks to the 'visitor' or 'complainant' as they are not asking for change. Rather, Berg (59) suggests affirming current successes and maybe, in time, these types will move towards being more ready to engage with therapy or identify other issues which they do wish to change, but it is not for the therapist to persuade the person who is not asking for change. Conceptualising 'types' of people with dementia in this way may be useful when designing or offering interventions, perhaps supporting professionals consider what the person with dementia's perspective of their 'problem' is. But, this does approach does seem to imply that a person with early dementia has a 'problem' to solve or change. Yet, as the concept of social health explained above (Section 1.7.3) suggests, often this may not be the case. It may be that people and systems around a person with dementia need to address contextual or environmental issues in order to support that person, rather than expecting the person themselves to change.

Also, both Berg's (59) typology of clients and the transtheoretical theory of change (58) appeared focused on the process and outcome of therapy, rather than the initial engagement as was the focus of my doctoral research.

Some existing approaches conceptualising the use of health services or health seeking behaviour offer insight and a more contextual approach to understanding readiness to use services. For example, the concept of 'candidacy' (60) highlights factors affecting use of health services. Given my concern that not all descriptions of interventions I was likely to hear about during interviews would encompass interventions aimed at promoting behaviour change, this concept illuminates potential issues that may affect uptake of services. The concept of candidacy was based on a review of evidence about access to NHS healthcare in the UK by potentially vulnerable groups (60). The concept describes how people's eligibility for healthcare is determined between themselves and health services and recognises the interplay between the individual and services, emphasising the dynamic, multi-dimensional and contingent character of access. The authors (60) also highlighted that service users can and do refuse offers of services, such as GP referrals to other services but did not discuss why this may be. However, this review did not publish the included studies on which the concept of candidacy was based. The examples of studies given did not include any people with dementia or dementia services and were focused on medical treatments, rather than psychosocial interventions. However, the concept of 'candidacy' as a continually negotiated property of individuals, subject to multiple influences arising from people, their social

contexts, allocation of resources and configuration of services may suggest that readiness to engage in psychosocial interventions by people with early dementia may involve the interaction of people affected by dementia, with services that may offer a range of different types of interventions.

In relation to people with dementia specifically, and how they may adjust and cope, Clare (28) suggested people with early Alzheimer's Disease can fall into one of two groups on a shared continuum. This continuum runs from self-protective responses, serving to maintain a prior or existing sense of self, to integrative responses, allowing for development and adjustment of the self-concept. Clare (28) contends that a process occurs whereby individuals register changes, react to the changes, try to explain the changes, experience the emotional impact of the changes and attempt to adjust to the changes. Clare (28) explains that all the strategies used by people to cope were aimed at achieving a positive outcome for the self, but in different ways. It may be that, depending where an individual is on this continuum of self-protective to integrative responses, people with early dementia are not ready to engage with interventions and may reject them, or accept them if they more towards self-integrative end of the continuum. Clare (28) concludes that interventions to support people with early dementia should be underpinned by an understanding of the coping strategies and processes people with dementia naturally use. Examples suggested were interventions aiming to encourage social contacts and support, reduce isolation, providing opportunities to talk about the experiences of dementia, helping people identify activities they can still engage in and enjoy (28) Such recommendations support my choice of a broad definition of psychosocial interventions (Section 1.7.5) as one not focused exclusively on interventions that have an explicit behaviour change focus or intended outcome.

A strength of Clare's work (28) was that people with dementia were interviewed twice, approximately three months apart. This perhaps facilitated the idea of a continuum which people moved along, over time. Interviewing people twice may have allowed analysis of how people talked about coping over time. However, three months is a relatively short time for changes in coping or adjustment to be reported or experienced. Further, this work only included those with Alzheimer's Disease and so may not be transferrable to those with other kinds of dementia, which my definition of dementia includes (Section 1.7.1).

Robinson et al (61) interviewed couples about receiving a diagnosis of dementia and how this subsequently affected their relationship and involvement in activities. This study did include both those with Alzheimer's Disease and vascular dementia. Robinson et al (61) suggest a model which illustrates an oscillating process couples go through in making sense

of the experience of early dementia. Also, both Robinson et al (61) and Clare (28) did not report data about people's engagement or acceptance or rejection of interventions offered by services. Findings reported focused on adjustment and coping in people's daily lives, examples of interventions engaged with or rejected were not reported. In contrast, the focus of my research is the interventions offered to people with dementia and how they (and others such as family members and staff) perceive and experience of those

Thus, it appears unclear what the process of change might be when a person moves from not being ready to engage with an intervention, to accept it initially and then engage with it over time. The literature discussed above suggests whilst individuals may change over time towards a readiness to engage in a behaviour change or an intervention and this movement may not be a linear progression. The process of adjusting to an illness or dementia specifically appears fluid moving across a continuum as described by Clare (28), 'oscillating' as described by Robinson et al (61) or cyclical as described within the transtheoretical model of change (58).

I was unable to identify a model or theory of behaviour change that had been applied to people with early dementia living in the community in relation to uptake of services or engagement with interventions. I considered then, asking people with dementia (alone or with a family member) and staff about interventions offered, without predefining or excluding specific types of interventions was a necessary first step. From there, I could seek to identify what led to uptake and a readiness to engage, initially, with interventions offered in practice.

I was also concerned that using an existing theory or model to frame my examination of this new topic area risked simply confirming this chosen model or theory, rather than using participants' own accounts to inform my findings. I made the decision to listen to people with dementia, family members and staff speak about their experiences in interviews, and then analyse and interpret their accounts unfettered by predetermined concepts or theories. Given this topic had not been researched before, applying an existing theory or model at such a preliminary stage of examining the topic seemed premature. Future studies may be better placed to examine whether existing theories or models had application to understanding the phenomena of acceptance and rejection of psychosocial interventions by those with early dementia.

1.7.7 Family members and the 'dyad'

I use the term family members to mean spouses, partners, relatives (child or other) or any other person who supports a person with dementia in an 'informal' or unpaid capacity.

Although the term 'family carer' or 'carer' is often used in policy and research literature. I decided not to use those terms because many of the family members of people with dementia I met when working on the VALID programme and over the course of this PhD did not refer to themselves using this language. Also, when consulting with the South Yorkshire Dementia Research Advisory Group (a Patient and Public Involvement group) as part of the VALID programme, group members had said that some people did not like or use the term 'carer'. However, when reviewing existing literature I use the term 'family carers' or 'carers' if those are the terms used in publications I am reporting. The term 'dyad' is used to mean both the person with dementia and the family member together.

1.7.8 Uptake, acceptance or rejection of psychosocial interventions

Uptake or take-up can be defined as *'the action of taking up or making use of something that is available'* and acceptance as *'the action of consenting to receive or undertake something offered'* (Oxford English dictionary). Rejection can be defined as '*the action of refusal, non-acceptance, declining, turning down'* (Oxford English dictionary). I use the terms uptake, take-up, acceptance or rejection (of psychosocial interventions) throughout this thesis.

1.7.9 Staff

I use the term 'staff' to refer to people whose paid work roles involve providing, referring to or signposting people with dementia and family members to psychosocial interventions. Examples of such staff might be doctors, nurses, occupational therapists, clinical psychologists, care assistants, care workers, or volunteers. These may be NHS staff or those working in the social care or voluntary sectors.

1.7.10 Model, theory and framework

The terms theory, model and framework are sometimes used interchangeably within the research literature (62,63). All involve naming concepts relevant to a particular question or topic and identifying their relationship to each other (63). In one of my research objectives (Section 1.6) I use the term 'model' and in Chapter 7 (Section 7.4), I present a framework. Theories generally have concepts amenable to hypothesis testing and that is not my aim. Models tend to have a narrower scope. Nilsen (64) contends a model typically involves a deliberate simplification of a phenomenon or a specific aspect of a phenomenon, need not be completely accurate representations of reality to have value and that a model is descriptive, whereas a theory is explanatory as well as descriptive. Nilsen (64) describes a framework as usually denoting a structure, overview, outline, system or plan consisting of various descriptive categories e.g. concepts, constructs or variables and relations between them that are presumed to account for a phenomenon. Frameworks do not provide

explanations they describe empirical phenomena by fitting them into a set of categories (64). I considered 'model' the most a suitable term to use at the start of this research, when defining my research objectives. However, by the time this research was completed, I reflected on my findings and how best to represent them visually. I decided framework was a more appropriate term for the illustration I designed to give an overview of the main influences on acceptance influences acceptance or rejection of psychosocial interventions identified by this research (see Chapter 7 Section 7.4).

1.8 Thesis structure

Chapter 1 explains why the topic is important and how my interest in the topic began. Dementia policy and research drivers, including the role of people with dementia in research are presented. I explain that there have been two phases to this research, a preliminary phase (phase 1) and the main study (phase 2). Research aims, objectives and research questions used to guide this this research are then presented, followed by definitions and key concepts used in this thesis.

Chapter 2 presents two different literature reviews. The first review was a preliminary scoping literature review completed in 2016 as part of the preliminary phase of this research, to try and identify what, if any existing research there was about uptake of psychosocial interventions by people with dementia. A main literature review was completed in 2019 as part of the main study. This review aimed to identify recent research evidence about psychosocial interventions and examine this body of evidence to identify what, if any, information it contained that was relevant to acceptance and rejection of psychosocial interventions by people with early dementia.

Chapter 3 presents the methodological approach used for the main study. This includes my epistemological and ontological perspectives, the qualitative research design and data collection methods. The way thematic analysis and triangulation of findings were conducted and findings disseminated are also described.

Chapter 4 presents findings from semi-structured face-to-face interviews I completed with people with dementia and their family members.

Chapter 5 presents findings from semi-structured interviews and one focus group I conducted with NHS and voluntary sector staff working with people with dementia and their families.

Chapter 6 presents the findings from both sets of interviews as overarching themes.

Chapter 7 discusses the findings from my primary research in the context of relevant contemporary research. Reflections are discussed and limitations of this research are presented. A framework summarising influences on acceptance or rejection of psychosocial interventions by people with early dementia is presented, which synthesises findings from the empirical work and the literature reviewed and summarises the key influences on uptake of interventions. Recommendations for policy, practice and research are made.

Chapter 8 is brings together my overall conclusions about the process and outcome of this research and highlights the unique contribution of this thesis to knowledge.

In summary, this research contributes to the evidence base for psychosocial interventions for people with early dementia after diagnosis living in the community. This has been achieved by identifying influences on acceptance or rejection of psychosocial interventions by people with early dementia.

Chapter 2 Reviewing the literature

This chapter presents two literature reviews. The first, preliminary review is a scoping literature review completed in 2016. The aim was to map existing evidence and identfiy if there was a research gap about issues affecting uptake of psychosocial interventions for people with early dementia after diagnosis living in the community. The second, main literature review was completed in 2019. This aimed to identify recently published evidence about psychosocial interventions and examine what, if any, information about acceptance and rejection of psychosocial interventions by people with early dementia, could be identified within this body of recent evidence.

For accuracy, in this chapter, when reporting findings from studies or reporting what other authors have said I have used the language they used to refer to their study participants or study criteria.

2.1 Introduction about the literature review process

When I began this PhD (October 2014-April 2015) a first step was to familiarise myself by reviewing evidence about psychosocial interventions and the experiences of people living with early dementia to inform the direction of my studies. I found that much research focused on interventions for family carers (for example (37,65–67)) or the experiences of people living with dementia (for example (28,68–71)). There was also a growing evidence base concerned with the evaluation of psychosocial interventions (for example (12,19,72–76)). Moniz-Cook and Manthorpe (42) highlighted the need to target interventions to individual need. Bunn et al (77) reviewed qualitative studies to identify psychosocial factors that shape patient and carer experiences of diagnosis and post-diagnosis treatment and identified a substantial body of qualitative evidence particularly about experiences of adjusting to life post-diagnosis. They recommended the need for further research to focus on the effectiveness of different psychosocial interventions, as have others (77,78). During this initial review phase I did not identify research about what influences people with early dementia to accept or reject psychosocial interventions.

Given this, I decided to conduct a scoping literature review. This was completed in 2016. As scoping reviews are used to map the existing literature or evidence bases, to identify research gaps and summarise findings from research (79–81), this appeared a suitable and

systematic method for a literature review. However, the outcome was that this scoping review identified a limited number of studies with relevant content. The methods, results, discussion and limitations of this scoping literature review are presented first in this chapter, in Sections 2.2-2.6.

When nearing completion of this PhD in 2019, I then considered how best to present an updated literature review. This main and more recent literature review is presented in Sections 2.7-2.13 of this chapter.

In preparation for updating the literature review, in 2019 I had I discussed potential approaches and search strategies with ScHARR Information Specialists and my supervisors. I trialled different search strategies to try and identify a manageable way to review the extensive psychosocial intervention literature, but attempts to do this indicated that potentially relevant papers I was already aware of would be excluded (see Section 2.8). Given this, I also tried alternative strategies; I ran searches of the Cochrane Library to identify trials or reviews about uptake or acceptance of non-pharmacological interventions without specifying dementia or other diagnosis, to try and identify potential search terms. This identified what I thought were three potentially useful terms: 'patient acceptance of health care', 'patient participation' and 'utilisation'. I then ran searches using these terms and other synonyms for uptake and acceptance (for example, uptake, service use, utilisation, compliance, participation, acceptability), along with synonyms for dementia and terms for psychosocial interventions I ran these searches in three databases (MEDLINE, PsychINFO and CINAHL). I identified 1,442 citations. However, initial screening identified that many did not concern my population of interest. It appeared that using the synonyms I had chosen for uptake and acceptance identified studies mostly about services providing care, such as acute hospitals, respite, social or home care services and many were focused on services for carers or reported carers perspectives. Therefore this strategy also did not appear to be an effective way to identify studies that may report or discuss issues relevant to uptake of psychosocial interventions by my target population.

ScHARR Information Specialists had suggested trying to identify if there were any existing reviews of psychosocial interventions, focused on a similar population of interest to my own. The rationale being that if such a review existed, it could offer me a list of studies about psychosocial interventions, which I could examine to ascertain if these studies reported any information about uptake or ready and willingness to engage in the interventions reported. I was aware a recently published scoping review of psychosocial interventions by Keogh et al (14). Therefore, I decided using the list of included studies published by Keogh et al (14)

offered me the opportunity to examine a pool of studies already selected for being focused on psychosocial interventions. This second, main and more recent literature review is presented in Sections 2.7-2.14 of this chapter.

2.2 The first literature review: a scoping review to identify evidence about uptake of psychosocial interventions post-diagnosis

This scoping review aimed to try and identify what, if anything, was reported about influences on uptake, acceptance or rejection of interventions. I also wanted to use the understanding gained to help inform a preliminary model of readiness to engage in psychosocial interventions which I aimed to try and further develop in Phase 2 of this research.

To help minimise bias, increase rigour and reliability, Arksey and O'Malley's (79) framework for completing scoping reviews was selected and five different stages completed in order to achieve this.

2.3 Methods used for this scoping literature review

Stage 1: The research question for scoping review

The review question was: '*What is known, from existing published research, about issues which may help or prevent take up of psychosocial interventions for people living with mild to moderate dementia after diagnosis, and their family carers, in the community?*'

Stage 2: Identifying relevant studies

Relevant studies were identified using MEDLINE, PsycINFO and CINAHL databases. My prior work had identified suitable concepts for the research question, so synonyms for these key concepts were used. Terms for dementia were combined using the operator 'AND' with terms for psychosocial (psychological, social, quality of life) and terms for intervention (treatment, therapy, rehabilitation, support). These terms were then combined with terms for 'after diagnosis' and 'post-diagnosis'. It was necessary to use synonyms for 'post-diagnosis' as searching on terms for psychosocial interventions and dementia alone generated thousands of citations, which was unmanageable within the resources and time available. An example of the search strategy used is appended (see Appendix 2.1).

Stage 3: Study selection

Inclusion/exclusion criteria were identified before carrying out searches and then developed post-hoc. This is a method used for scoping reviews, and one which differentiates them from systematic reviews (80). The inclusion and exclusion criteria are presented in Box 2.1.

Box 2.1 Summary of scoping review inclusion and exclusion criteria

✓ Any design / date; English only
✓ Study population: majority community living people with mild-moderate dementia, their family carers and/or staff working with them (but not family members or staff alone)

Focus of study:
✓ Psychosocial interventions offered post-diagnosis to people with dementia alone or with a family member (not family member only interventions)
OR
✓ Experiences of people with dementia or family members about life post-diagnosis
AND
✓ Relevant content identified about people taking up or rejecting psychosocial interventions post diagnosis, or staff/services providing post-diagnostic support

Exclusions: commentary/opinion, protocols, study population predominately young onset dementia, pharmacological studies

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Stage 4: Charting the data
Relevant information from included studies was extracted and summarised in tables to enable identification of themes across the included studies.

Stage 5: Collating, summarising and reporting
The search yield was 109 hits and 92 citations after duplicates were removed. After screening abstracts, 69 were excluded and 23 selected as potentially relevant. Twenty one full text articles were assessed for inclusion (two could not be obtained via inter library loans). No studies were found that directly addressed the main review question.

Key references from included studies were not identified. Consultation to confirm findings or identifying grey literature were also not carried out as suggested by Arksey and O'Malley as possible additional strategies (79), given limited resources.

However eight studies reported results or discussion that had some relevance to uptake of psychosocial interventions and were included for charting (see Appendix 2.2 Flowchart of study selection process).

2.4 Summary of main characteristics of included studies

Table 2.1 presents the main characteristics of the eight studies included for charting.

Table 2.1 Main characteristics of studies included for charting in the scoping literature review

Author, date (thesis reference list number)	Country	Main focus of study	Sample characteristics (including type and severity of dementia, community or other living situation)	Design and methods	Theory / models	Most relevant main findings
Qualitative studies						
Innes et al 2014[1](82)	Scotland	Difficulties and satisfactions with the diagnostic process and post-diagnostic support in large remote rural area	N=18 (6 people living with dementia, 12 family members) who had experienced the diagnostic process 6 months before interview Type and severity of dementia not reported Living situation not reported	Consultation and semi- structured interviews Paired interviews offered if recommended by gatekeeper	None reported	Post-diagnostic support discussed. Themes included needs of service users, services accessed and satisfaction with memory services.
Gorska et al 2013[2](83)	Scotland	Understanding of the lived experience of people living with dementia about their service related needs	N=31 (12 people with dementia, 19 unpaid carers) ;10 people with AD, 3 with vascular dementia, 1 Mixed, 6 unspecified dementia 8 mild, 5 moderate, 7 severe (includes people cared for by the carer participants). Diagnosis and severity confirmed by health services assisting with recruitment 68% sample community living, 32% residential	Semi-structured narrative interviews People with dementia interviewed separately, one wished to be interviewed with carer	None reported	Post-diagnostic support discussed. Sub-themes included coordination, continuity and access to non-pharmacological treatment to support identity and social engagement.

Author, date (thesis reference list number)	Country	Main focus of study	Sample characteristics (including type and severity of dementia, community or other living situation)	Design and methods	Theory / models	Most relevant main findings
Mountain & Craig 2012 (84)	England	Obtaining views of people with dementia and carers about their experiences and interventions they consider can assist independence and quality of life post-diagnosis. To identify topics for inclusion in a self–management intervention	Interviews: N=10 (5 people living with dementia, 5 carers). Inclusion criteria described as for people in the 'early stages', able to volunteer themselves independently. Consultation: N=15 (7 people living with dementia, 8 carers): all had diagnosis for at least 6 months prior, some had lived with dementia for over 2 years Type and severity of dementia not reported	Semi-structured interviews and consultation. People with dementia given choice of single or paired interviews	Social cognitive theory referred to as informing intervention development	Themes included diagnosis and experience of subsequent interventions; information provided to people with dementia; carer perceptions of available support; managing dementia alongside other conditions, managing unexpected symptoms, maintaining meaningful roles, interventions and modes of delivery to meet needs.
Ward-Smith & Forred 2005[3] (85)	USA	Experiences of a family member diagnosed with AD, participation in the diagnostic process and compliance with the services' recommendations post- diagnosis	N=18 caregivers caring for a person who had had diagnosis of AD confirmed by the programme within last 6 months Convenience sample from a dementia assessment service (a 1 day out-patient programme)	Semi-structured interviews	None reported	Themes 'plans for the future and recommendations' Recommending Power of Attorney and Living Will were mentioned as the most helpful recommendation by seven participants. All were frustrated with recommendation to begin seeking long term care facilities. None were able to attend a local support group, time constraints were the primary reason.

Author, date (thesis reference list number)	Country	Main focus of study	Sample characteristics (including type and severity of dementia, community or other living situation)	Design and methods	Theory / models	Most relevant main findings
Quantitative studies						
Phung et al 2013 (86)	Denmark	Efficacy at 36 month follow-up of a psychosocial counselling and support intervention lasting 8-12 months	N=330 community dwelling dyads (people with mild AD at baseline, and their caregivers) (200 at 36 month follow up, 130 patients lost to follow up, reasons given) Inclusion criteria: confirmed diagnosis of AD, Mixed AD and vascular dementia or Lewy Body Dementia; home living, diagnosed within last 12 months, Severity based on MMSE score	Randomised Control Trial (RCT)	Intervention based constructivist approach	No positive effect for this psychosocial intervention (counselling and support) found at 36 month follow-up.
Carpenter et al 2008[4] (87)	USA	Short term changes in depression and anxiety after receiving a dementia diagnosis	N=90 participants & companions 28 no dementia, 41 very mild dementia, 21 mild dementia Clinical Dementia Rating (CDR) scale used to assess severity Type of dementia not reported	Pre and post-diagnosis telephone interviews; Person with dementia and companions interviewed separately	None reported	No significant changes in depression were found in people with dementia or companions, regardless of diagnostic outcome or dementia severity. Anxiety decreased substantially after diagnostic feedback in most groups.
Williams et al 1995[5] (88)	USA	Carer perceptions of functional decline of people with dementia, most problematic behaviour for carers at diagnosis and 3 years; carers information	N=30 carers caring for people with dementia AD n=14, 'senility'/memory loss n=6 arteriosclerosis n=4. At diagnosis 87% of sample living at home, 13%	Postal questionnaire pre-diagnosis and 3 years post	None reported	Questions carers most wanted answered at time of diagnosis were possible treatment, future course, cause of symptoms. At 3 years post-diagnosis these were: future course, possible

Author, date (thesis reference list number)	Country	Main focus of study	Sample characteristics (including type and severity of dementia, community or other living situation)	Design and methods	Theory / models	Most relevant main findings
		needs at these times	in nursing homes. At follow-up, half those still alive living at home, half in nursing homes. Severity not reported.			treatment and disease inheritance.
Systematic review						
Bunn et al 2012 (77)	England	Evaluated qualitative evidence re: how people adapt to diagnosis. Reviewed psychosocial factors shaping patient and carer experiences of diagnosis and early treatment	126 studies included 40% of included studies did not specify type of dementia; where they did the majority had AD. Focused on community dwelling participants, excluded studies in long term care settings. 26 studies reported stage of dementia, using MMSE or similar, all but two were mild-moderate range	Systematic literature review of qualitative studies	None reported	Themes about 'pathways through diagnosis', 'resolving conflicts to accommodate a diagnosis' (including acceptability of support, focusing on present/future, use or avoidance of knowledge strategies) 'support to minimise impact of dementia'

[1-5] majority of sample met inclusion criteria or judgement made that majority of sample likely to meet inclusion criteria AD Alzheimer's Disease MMSE mini mental examination CDR Clinical Dementia Rating Scale

Location and date of studies included

As Table 2.1 shows, of the eight studies included for charting, four were carried out in the UK (two in Scotland, two in England), three in the USA, and one in Denmark and were published between 1995 and 2014.

Study design

Four papers employed qualitative research designs, three quantitative and one was a systematic literature review of qualitative studies.

Focus of studies

As shown in Table 2.1, the main focus of the included studies varied. Three of the qualitative studies (82,83,85) focused on experiences of services post-diagnosis from the perspective of people with dementia and their family carers. One (84) focused on the development of a self-management intervention. Of the three quantitative studies, one (86) examined long term efficacy of a counselling and support intervention, as part of a randomised control trial (RCT). One examined changes in depression and anxiety for people with dementia and their carers after diagnosis (87) and the other, carer perceptions of functional decline in people with dementia and carer information needs (88). The systematic literature review focused on psychosocial factors shaping patient and carer experiences of early diagnosis and treatment (77).

Sample characteristics, severity and type of dementia

Sample sizes in the included studies varied. For the qualitative studies numbers of participants ranged from 10 to 31. For the quantitative studies sample size ranged from 330 (86) to 30 (88).

In five studies, people with dementia and their family carers were participants (82–84,86,87). Two studies (85,88) involved family carers only. Bunn et al (77) reviewed 102 studies, reporting that 61 included participants with dementia and 72 involved family carers of people with mild cognitive impairment or dementia.

All studies involved participants living in the community, with mild to moderate dementia. One (83) did involve a mixed sample of 12 people with dementia and 19 unpaid carers, 68% living in the community and 32% living in residential settings. Another (87) included 28 participants who did not have dementia and 62 participants who had either very mild or mild dementia.

Five studies reported the type of dementia diagnosis (77,83,85–88), Alzheimer's Disease being the most common. Two studies, both qualitative, did not report type of dementia (82,84).

Severity of dementia, and methods used to establish this were reported by three studies (83,86,87). The systematic literature review (77) described whether included studies had reported on type of diagnosis, severity and methods used to establish severity, or not.

Study methods
Four studies used semi-structured interviews (82–85). Two of these also used consultation methods (82,84). Three studies used questionnaires. Phung et al (86) used standardised assessment questionnaires, as part of an RCT. Carpenter et al (87) used questionnaires for telephone interviews. Williams et al (88) used postal questionnaires.

Of the five studies which interviewed people with dementia (82–84,86,87) all described whether the person with dementia was interviewed alone or with a family carer. Three reported giving participants the option of being interviewed alone or as a dyad (82–84). For all studies it was not possible to identify whether analysis and reported results were based on responses from people with dementia and their family carer separately, or together as a dyad.

Use of models or theory
Most studies did not make explicit reference to theories or models. One (84) referred to social cognitive theory, as having informed the development of a lifestyle intervention, which in term informed the self-management intervention for people with dementia. Another (86) reported that the intervention was based on a constructivist approach.

Quality assessment
As this was a scoping review, studies were not included or excluded on the basis of quality. However all charted studies were critically appraised using CASP checklists (89). All had used appropriate methods for their research questions suggesting that findings were reliable and trustworthy.

Relevant content related to influences on take up of offers of psychosocial intervention post-diagnosis was charted for the eight included studies, under the headings presented in Table 2.2.

Table 2.2 Summary of content charted for the scoping literature review

First author, date (thesis reference list number)	Possible influences on acceptance or rejection of psychosocial interventions	Type of influence	Type of recommendations relevant to take up
Qualitative studies			
Innes et al 2014 (82)	Identified unmet needs for information, support for carers was appreciated but cost and logistical challenges for people in rural locations could affect take up. Suggest that failure to address personal preferences for support and lack of alternatives (for example only day centres being available) could lead to rejection of services.	Services not meeting preferences or needs	Tailoring and targeting: recommend personal preferences for support should be catered for
Gorska et al 2013(83)	Poor coordination and communication between different services experienced. Carers believed they were responsible for coordinating services and keeping appointments. Need for continuity of staff expressed, and lack of this as causing anxiety and distress for the person with dementia. Wanting access to services that can help address changes brought about by dementia. Limited resources and waiting times reported.	Services not meeting preferences or need; interacting with individual experiences of dementia	Coordination of services: recommend single point of access may be helpful.
Mountain & Craig 2012(84)	Reported delays in post-diagnostic support or referral to services; not knowing how or where to look for information/support; services offered at locations far away; finding unfamiliar environments stressful and eroding independence. People with dementia reported majority of information was aimed mainly at carers. Managing dementia alongside other conditions reported as a main theme. Preferences expressed for post-diagnostic support locally or at GP surgeries and for separate groups for people with dementia and carers.	Services not meeting preferences or needs	Tailoring and targeting: tailoring of individual programmes essential
Ward-Smith & Forred, 2005 (85)	Carers reported they were given lots of information during diagnosis assessment but found much of it not applicable, for example services not available in their area, community services not perceived as useful within the time frame and using support groups regarded as not feasible.	Services not meeting preferences or needs, interacting with carer characteristics	Tailoring and targeting: temper recommendations for placement until the family is ready.
Quantitative studies			
Phung et al 2013 (86)	When discussing reasons why positive effect at 36 months was not found for this intervention, authors suggest some dyads may not have required the type and intensity of intervention offered, when they were experiencing only mild dementia.	Individual experiences of dementia (mild symptoms as potential influence)	Tailoring and targeting: suggest needs should be assessed, intervention offered only to those needing it and regular follow up to identify needs requiring intervention

First author, date (thesis reference list number)	Possible influences on acceptance or rejection of psychosocial interventions	Type of influence	Type of recommendations relevant to take up
Carpenter et al 2008 (87)	89% diagnosed with dementia and 93% of companions reported they felt capable of obtaining additional information and assistance. Authors suggest through gaining knowledge and a treatment plan, individuals may realise they can take an active part in managing the illness.	Individual experiences of diagnostic process as potential influence on acceptance of support	None identified
Williams et al 1995 (88)	All families were encouraged to read a book called '36hr day' & obtain durable power of attorney. Reported remaining/unmet needs for information for carers. Appears referral to Alzheimer's Society and recommendations were the same for all service users. 15 types of pre-specified informational needs including psychosocial needs were included in the questionnaires used.	Individual experience of dementia (carer information needs as potential influence)	None identified
Systematic review			
Bunn et al 2012 (77)	Ambiguities within the included literature, about trying to accommodate dementia diagnosis reported. For example, struggles to preserve a pre-dementia identity yet adapt; carers feeling torn between protecting yet promoting independence for the person with dementia; tension existing between maintaining social contacts and strategies to minimise impact of dementia; peer support was reported as beneficial but some studies reported a negative impact by showing what the future holds. Some studies reported memory clinics experienced as shocking/frightening. Studies identify need for post-diagnostic support. GP role as key facilitator to accessing services highlighted. Alzheimer Society services reported as valued. Information needs found to vary over time. Timing of referral to community groups possibly key and such decisions likely facilitated by ongoing, therapeutic relationships between individual with dementia and practitioners.	Services not meeting preferences or need; interacting with individual experiences dementia	Tailoring and targeting: recommend information provision needs to be flexible in timing and format and ongoing assessment of needs required

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The information summarised in Table 2.2. was synthesised and three themes about influences on take up of psychosocial intervention post-diagnosis were identified, and are now presented.

2.5 Themes identified from this scoping review

Theme 1: S*ervices not meeting needs or preferences*

Four studies reported that participants felt the intervention or post-diagnostic support they were aware of or experienced had not met their individual needs or preferences (82–85). The systematic review by Bunn et al (77) also reported similar findings; some studies they identified found participants experienced attending memory services as shocking or frightening (90,91). Lack of alternative options was noted, for example only day care or group interventions being offered (82,84,85). Limited resources and waiting times (83) also affected experience of services offered.

The consultation conducted by Mountain and Craig (84) reported that people with dementia considered that the majority of information given to them post-diagnosis was aimed at their carers. Górska et al (83) reported accounts of poor coordination and communication between services. Practical issues, such as services not being offered locally, travel costs, or at times when carers of working age could not attend (82,84,85) were also identified.

Two studies (83,85) discussed characteristics related to individuals or dyads, suggesting an interplay of these issues with the way services delivered interventions. For example, lack of continuity of staff causing anxiety and distress for people with dementia (83) and some family carers who were working could not attend support groups (85). The following quote, in the work of Ward-Smith and Forred (85), one participant voice illustrates this interplay of individual characteristics with style of service provision, resulting in unmet needs *"...Both of us work and mom has never been a social person, so day care is not an option"* (p.92).

This interplay of service experiences with personal preferences and needs was also indicated by Bunn et al's review (77). This review found that peer support could be beneficial, but also had the potential for negative impact for some, by showing what the future could hold (92). Bunn et al (77) identified tension between trying to maintain pre-dementia identities, whilst trying to adapt to the diagnosis, and trying to maintain a social life and yet use strategies to minimise the impact of dementia.

Theme 2: *Individual experiences of living with dementia*

For three studies (86–88) individual or dyadic influences that potentially could affect take up of the offer of intervention were identified. These were concerned with the impact of dementia on the person, carer or dyad. For example, Phung et al (86) suggested that dyads experiencing mild dementia and lacking severe symptoms perhaps did not require the support offered by the intervention, at this stage post-diagnosis. This was presented as a possible reason for no positive effect of a psychosocial intervention at 36 month follow-up. Carpenter et al (87) reported no significant changes in depression or anxiety in participants after receiving a diagnosis of dementia, and that both people with dementia and their carers felt capable of obtaining additional information and assistance, suggesting feeling capable of this may help individuals take an active part in managing their illness. The finding that diagnosis itself did not lead to depression, and decreased anxiety, is positive. The work of Williams et al (88) led to them terming the informational needs of carers at diagnosis and three years after as 'information about future course', 'possible treatment' and 'disease inheritance'.

Theme 3: *Targeting and timing intervention according to need*

Six studies recommended or discussed the importance of targeting and tailoring interventions (77,82–86). Flexibility and responsiveness according to need was promoted, but none of the studies gave specific recommendations about optimal times for offering post-diagnostic support. Innes et al (82) found that catering for personal preferences was important , with failure to do so leading to potential rejection of services. Górska et al (83) recommended a single of point of access, as a way of potentially facilitating access to post-diagnostic support. Mountain and Craig (84) suggested that tailoring self-management programmes to people's needs was essential to facilitate engagement. Their participants expressed preferences for post-diagnostic support being offered in their own locations or at GP surgeries, and for separate support groups for people living with dementia and carers. Ward-Smith and Forred (85) recommended that the guidance to start looking for placements for their relatives should not be given until the family is ready. Phung et al (86) suggested practitioners should not offer psychosocial interventions indiscriminately to all people with very mild dementia and their care-givers, but rather assess their needs in order to offer interventions to those that need them. They recommended that interventions could be designed so that those with greater needs at presentation to services receive more intensive intervention, than those with less assessed needs. Bunn et al (77) suggested assessment of needs, the timing and format of information provision should be ongoing and flexible. They highlighted the role of the GP in facilitating access to services, although it was unclear whether this refers to diagnostic or post-diagnostic services, or both. Bunn et al (77) also

suggested timing of referral to community groups could be key, and likely to be facilitated by therapeutic relationships between people with dementia and practitioners.

2.6 Discussion

The findings from this scoping review offered an initial understanding of influences on uptake of psychosocial interventions for people with early dementia. Findings helped inform Phase 2 of this research and the creation of a preliminary model of readiness to engage in psychosocial interventions (presented in Figure 2.1). Although no studies researching influences upon reasons for acceptance or rejection of interventions were identified, eight studies contained some relevant information. Overall, this review demonstrated the challenges of trying to identify literature focused on uptake of psychosocial interventions. This process involved iterative analysis and synthesis (81) and my own interpretations to try and integrate findings. This underlined the knowledge gap and need for phase 2 of this PhD research. However, there were also some limitations.

I carried out all searching, screening, charting and reporting alone. To minimise this potential bias I used academic supervision to discuss uncertainties and application of inclusion and exclusion criteria.

Also as Bunn et al (77) found not all studies reported type of dementia diagnosis or severity, how severity of dementia was assessed, or where participants lived and most researched populations accessible to the researchers. These populations may have different attitudes to their needs and interventions offered, or may not have similar characteristics compared to the wider population of people with early dementia. These issues may affect transferability of findings to understanding uptake of interventions by people with early dementia, living in the community. Also whilst the quantitative studies had larger numbers of participants, ecological validity remains a consideration. For example, studies were carried out in different countries, with different health care systems and dementia services. Indeed, the type of dementia services and interventions offered varies within, as well as between countries.

I used terms for 'post-diagnosis' to focus the search. Yet, there did not appear to be a common definition or terminology used for 'post-diagnosis' or 'after diagnosis', 'mild to moderate' or 'early' dementia, used within the dementia research literature. Therefore, my strategy may have excluded some relevant papers. For example some work by Clare et al (for example, ((28,93,94)) was not identified despite being focused on my target population. Perhaps this was because the term post-diagnosis was not used, rather such papers refer to

'early stage' or 'early' Alzheimer's Disease. Although such papers may not have contained information relevant to uptake this made me question the search strategy. I reflected that using the term 'post-diagnosis' to narrow the search was problematic, as it is fraught with problems of interpretation and meaning. I concluded that research about uptake of psychosocial interventions is new territory and identifying relevant research literature was a challenge for which I would need to develop an alternative search strategy in future when presenting more recent research evidence in this thesis.

2.6.1 How findings from this scoping review informed design and methods for the main study

The findings from this scoping review confirmed that a qualitative approach for the main study was appropriate given this was an under researched area (95). Also, the lack of primary research about influences on uptake of psychosocial interventions indicated the need for primary data collection to explore this topic directly with people with dementia, family members and staff.

These findings also made me consider methods I would use in the main study. For example, I considered how I could best obtain information about type and severity of diagnosis, as recommended by Bunn et al (77).The way studies had recruited mixed populations of community living people and those attending day care or living in residential settings or reported limited information about sample characteristics focused my research question to specify the population of interest for my primary research and the main literature review. Bunn et al (77) had also noted that experiences of those affected by Alzheimer's Disease may not be directly transferrable to people with other types of dementia and that little is known about those who do not access services, the oldest old and those who have co-morbid health conditions. Yet it appeared such issues may influence uptake of interventions by people with dementia. Therefore I wanted to report these characteristics to aid transparency and judgments about the transferability of my research. Thus, these findings informed decisions about the kind of data I wanted to collect when recruiting participants for my research, the research instruments I designed and interview methods I used. Most studies included in the scoping review did not report the process for conducting dyad interviews, challenges experienced when conducting interviews with people with dementia alone or jointly with family members, how data from dyad interviews was analysed or whether family accounts may have dominated joint interviews. With the exception of Mountain and Craig (84), included studies did not discuss the methods used to engage participants with dementia and facilitate communication during the research process. I

considered how to address these issues in the empirical work described in this thesis and describe my approach in Chapter 3.

2.6.2 How scoping review findings informed the preliminary model of readiness to engage

The key influences identified, that may influence people with dementia's responses to interventions that informed the preliminary model of readiness to engage were:

- Service characteristics: For example if there were a lack of alternative options to day care, convenient times and locations, ease and cost of travel, lack of consistent staff or co-ordination between services or waiting times, the role of the GP, and timing and format of information provision.

- Individual characteristics of the person with dementia and the family member: For example, personal experiences of dementia, severity of dementia, milder or more moderate symptoms and the impact of these on people's lives, mood states post-diagnosis, whether people felt capable of seeking information and support and preferences for particular types of information or separate groups for people with dementia and family members.

The findings from the secondary analysis of existing data completed during the preliminary phase of this research (see Chapter 1 Section 1.5 and Appendix 1.2) also fed into the development of this preliminary model of readiness to engage. This preliminary model is presented in Figure 2.1.

Figure 2.1 Preliminary proposed model of readiness to engage in psychosocial interventions after diagnosis by people living with early dementia in the community

Family member (if person with dementia has person supporting them regularly)

Relationship & caring

Person with dementia

Individual account/experience of dementia, impact and severity
Health and co-morbidities
Experience of services
Value activity and routine

Want support?

Not ready to engage

Consider offer

Ready to engage

(may start/drop out/not fully engage)

Clinician & Service context
WHEN offers made
HOW offer communicated
WHO offers
WHAT:
Types of intervention offered
(qualities and appeal)
Location convenience expense

2.7 The second literature review: updating the evidence, the main literature review

As explained in Section 2.1, in 2019, following the completion of the primary research for this doctoral study, I needed to identify the most relevant recent evidence about acceptance and rejection of psychosocial interventions. The scoping review completed in 2016 had not identified any papers focused exclusively on uptake of psychosocial interventions by people with early dementia living in the community and given the limitations of the search strategy employed for that review (see Section 2.6) an alternative strategy was needed.

I had intended to propose a model of readiness to engage, based on both my empirical work and the findings from both literature reviews. However, after completing and reflecting upon both these aspects of my research I decided proposing a summary framework of influences on acceptance and rejection of psychosocial interventions rather than a model of readiness to engage was a more appropriate way of representing my findings (see Chapter 7 Section 7.4).

2.8 Methods to identify relevant recent evidence

The aim of this main review was to identify relevant recent evidence about acceptance and rejection of psychosocial interventions, by people with early dementia living in the community, using systematic methods.

I trialled searches for synonyms of psychosocial interventions ('psychological' OR 'social' OR 'rehab*' OR 'therap*' AND (programme* OR program* OR intervention* OR treatment*) with terms for dementia. Unmanageable numbers of citations were generated, for example over 6,000 citations just within one database (MEDLINE). I also trialled just using the term 'psychosocial intervention' with terms for dementia, but this identified a limited number of citations (117 on MEDLINE). When these were screened I found none that related to my population of interest (i.e. people with early or mild to moderate dementia living in the community) and interventions of interest. This was likely because terminology for psychosocial interventions differs across and even within countries. Also, the term 'psychosocial intervention' may not be used by all those reporting these interventions. For example, a Spanish author used the term 'non-pharmacological' interventions (12). Narrowing the search in this way indicated potentially relevant papers would be excluded.

I identified a scoping review published by Keogh et al (14) in 2019, focused on psychosocial interventions specifically for people living with mild to moderate dementia in the community. This scoping review had aimed to:

"…*identify the nature of the evidence for the use of psychosocial interventions that might feasibly be delivered through health services for community dwelling people with mild to moderate dementia*" (14) (p.642)

The review by Keogh et al (14) offered the opportunity examine existing recent evidence about psychosocial interventions for community living people with mild to moderate dementia, and identify if the studies included reported information about what may influence acceptance or rejection of interventions, and if so, what they reported.

I adapted methods recommended for undertaking scoping reviews (79) to complete this review (see Appendix 2.3). Details of the inclusion criteria applied by Keogh et al (14) in their scoping review are appended (see Appendix 2.4). Given scoping reviews focus on mapping a topic and providing an overview, quality assessment of the studies included was not completed (14).

Box 2.2 presents the criteria I used to identify which of the studies included by Keogh et al (14) were suitable to include in this review. I also supplemented this strategy by searching for studies published after Keogh et al's (14) review. This involved searching the Interdem website and asking academic experts.

Box 2.2 Criteria used to identify relevant evidence about intervention uptake from studies included in the Keogh et al (14) **scoping review**

- Any design
- Studies include information relevant to why people with dementia may take up or reject psychosocial interventions

Excluded: studies involving mixed populations of people with early or mild-moderate dementia living in the community with people with dementia living in residential or nursing care settings or attending day care services, unless people with early or mild to moderate dementia are the majority and the results are presented separately

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I identified twenty six studies from the Keogh et al review (14) which met the criteria in Box 2.2. Two additional studies were identified. One of the additional studies was my own paper (34) and one by Clare et al (20). The main characteristics of these 28 studies are now presented. Further details are appended (Appendix 2.5)

2.9 Main characteristics of included studies

Study location

Six studies were completed in the USA (96–102), six in England (34,103–107), four in England and Wales (20,108–110), two in Denmark (111,112), two in Germany (113,114), and one each in Sweden (115), Scotland (116), Wales (117), Netherlands (19), Brazil (118), Australia (119), Canada (120) and Hong Kong (121).

Study designs and aims

All but one of the included studies were designed to evaluate psychosocial interventions or examine aspects of feasibility or delivery. The one exception was my own paper which aimed to identify influences on uptake of a community occupational therapy intervention using a secondary qualitative analysis (34). Fourteen (19,20,113,115,119,121,99,102,104,108–112) employed RCT designs to determine efficacy of interventions and three other RCTs were pilot studies (107,114,117). Ten (96–98,100,103,105,106,116,118,120) involved other designs, such as pre/post-test case control or pilot studies to determine feasibility of recruitment, acceptance, delivery or training, service or project evaluations. Four studies reported qualitative interviews completed with people with dementia and family members together, or people with dementia alone, to explore the experiences or acceptability of interventions, as part of RCTs or other study designs (34,103,109,117).

Study populations

All studies included people diagnosed with dementia. Ten studies involved people specifically with a diagnosis of Alzheimer's Disease (AD) (96,97,104,107,111–113,118,119). Twelve studies included people with different types of dementia diagnosis, including AD, Vascular Dementia (VD), and 'mixed type' dementias (20,34,120,121,102,104,105,109,110,115–117). Six studies did not report different types of dementia diagnosis (19,98–100,103,106).

Twenty two studies involved a family member in the intervention (19,20,109,111–119,34,121,97,99,100,103,104,106,108), although two did not require participation of the family member (100,103). Six studies involved people with dementia alone (96,98,102,105,107,120).

For five studies it was necessary to infer that the sample was community living from other information reported, as this was not explicitly stated (96,97,106,117,120). For example, when participants had been recruited from outpatient clinics or memory services or had been required to travel to study sites.

Severity of dementia and how this was reported

Thirteen studies included people with mild to moderate dementia, as determined by using the Mini-Mental State Exam (MMSE) (122) to identify mild-to-moderate cognitive impairment alongside a dementia diagnosis (20,99,117,120,121,103,105,107–109,111–113). Three studies (96,102,118) used the Clinical Dementia Rating Scale (CDR) (123) to confirm inclusion, and of these, three included people with a mild to moderate rating (34,102,118) and one included those with a mild or very mild rating (96). One used both the MMSE and CDR, requiring a score of 1 indicating mild symptoms of dementia (104). Four studies reported mean MMSE scores (98,114,116,119). For those studies I inferred the majority of the samples were people mild to moderately affected by dementia. Six studies used other types of assessments to indicate mild to moderate severity of dementia (19,97,100,106,110,115).

Type of interventions offered

Two studies offered cognitive rehabilitation (20,108). One involved cognitive training for the person with dementia (96). Two studies involved memory training for the person with dementia with family member support (97,115) and two involved cognitive stimulation delivered by family members (109,116). One study offered an educational course for those newly diagnosed (98) and two offered self-management group programmes (103,117). Four studies involved community or home based occupational therapy programmes (19,34,99,113). One study involved community based services and an Alzheimer's Association delivering personalised consultations (100). Five studies involved physical exercise programmes (111,114,118,119,121). One study involved brief psychotherapy for people with dementia (104) and one group psychotherapy for people with dementia (105). One study involved group reminiscence therapy for people with dementia and family members (110). Two studies involved other types of group support, one including some family member involvement (106) and one with people with dementia alone (120). Three study interventions involved multi-modal approaches (102,107,112). One of these involved a mixture of tai-chi, cognitive behavioural therapies and a support group (102), one a group intervention involving different activities delivered by a nurse (107) and one involved counselling, education and support activities alongside some family member participation (112).

Group interventions

Nine studies offered group based interventions (98,102,103,105–107,110,117,120,121). Of these, seven involved groups for people with dementia alone (98,103,105–107,117,120), although two included carers attending one or some sessions (103,117) and two involved joint groups for people with dementia and a family member (110,121).

Tailored interventions for the person with dementia or dyad

Nineteen studies offered tailored interventions (19,20,109,111–116,118,119,34,96,97,99,100,102,104,108). Of these, 15 were offered to the person with dementia and a family together (19,20,114–116,118,119,34,97,99,108,109,111–113) and four (96,100,102,104) to the person with dementia alone.

2.10 Summary of information relevant to intervention uptake

Within the 28 studies, I identified the following types of information relevant to identifying influences on uptake:

- recruitment difficulties

- reasons for exclusion and declining to participate

- reasons for limited engagement during interventions

- participant views about acceptability or expectations for interventions

- discussion by authors about potential reasons for their results or limitations of their studies

Relevant information was extracted, sorted into similar categories and summarised as themes to capture the main influences on uptake identified (for details see Appendix 2.6).

I extracted details of reasons identified for drop out, non-attendance or engagement in interventions, which I grouped together and summarised as 'reasons for limited engagement during interventions'. I was uncertain whether such reasons were relevant to uptake, because these events occur after participants have started an intervention rather than before. Yet, it also seemed reasonable to consider that issues identified as affecting engagement with the intervention over time, such as organisation, motivation, fatigue, stress and cognitive function and the role expected of family members may likely influence acceptance or rejection of interventions at the outset.

The way studies reported exclusions or non-participation varied. Despite differences in reporting, these studies indicate that many potentially eligible people were excluded or rejected intervention offers, indicating that uptake of the interventions offered by these studies was variable. Yet examination of the reasons for exclusion or non-participation was limited and details about specific reasons why people were excluded were not always reported. Also, many studies reported 'no contact' as a reason for exclusion but this information does not illuminate reasons for intervention uptake, although it indicates that this population can be hard to reach initially.

My analysis of the information extracted from the included studies was informed by themes already identified within the empirical research conducted (Chapters 4-6) and the scoping literature review, as I was seeking to confirm whether or not similar issues were reflected within these selected studies.

2.11 Themes about influences on acceptance or rejection of interventions identified from the included studies

I identified five themes from this review of recent evidence about psychosocial interventions to capture influences on acceptance or rejection of interventions. These themes are:

1) Co-morbidities, personal, social and living circumstances

2) Intervention characteristics: whether interventions are perceived as having potential to meet needs or preferences

3) Service and staff role

4) Key role of family members

5) Dementia related characteristics or behaviour

Theme 1: *Co-morbidities, personal, social and living circumstances*
All studies identified issues such as ill health personal, as impacting on intervention participation. Ill health of either the person with dementia or family member was often reported as a reason for recruitment difficulties, exclusion, declining to participate, non-attendance at intervention sessions or withdrawal. This included hospital appointments, falls, or the death of either person (19,98,113,117–119,121,100,103,105–107,109,110,112).

Other personal, social or living circumstances were also cited as reasons for exclusion or declining to participate. These included moving home, moving into residential care, taking holidays or having other commitments (99,107,109,110,114,116,120).

Theme 2: *Intervention characteristics: perceived potential to meet needs or preferences*
One reason reported for declining to participate in a study of individual cognitive stimulation therapy was that some preferred group activity, were doing their own activities at home or viewed the intervention as unsuitable (109). When evaluating psychotherapy groups, Cheston et al (105) noted that such groups would not appeal to some potentially eligible people, just as some people without cognitive problems may not want to participate in group psychotherapy. When evaluating joint reminiscence groups, Woods et al (110) reported

some carers expressed discomfort with these groups and that 'does not like groups' was a reason for declining. Three other studies highlighted other aspects of interventions which did not appeal: some people did not want to meet other people with dementia (107); the potential upset intervention sessions may cause was given as a reason for declining a brief psychotherapy intervention (104); some people with dementia or carers declined because they were not interested in exercise, the focus of intervention (119). Gitlin et al (99) reported 'wanting information only' as a reason why dyads were excluded from an occupational therapy led intervention. Similarly, 'intervention not required' was reported by Galvin et al (100). It was unclear whether potential participants or staff had reported this reason. One study (120) noted that their referrals did not reflect the ethnic diversity of the locality.

Reports of qualitative interviews undertaken with dyads or people with dementia alone to examine acceptability or expectations for interventions highlighted that people with dementia and family members had participated because they perceived the intervention might meet their needs for support, a desire to maintain independence or find new meaningful activities to engage with (34,103,117). Also, my own paper had identified that despite limited expectations or understanding of what intervention might involve, some participants had been willing to try it (34).

Theme 3: *Service and staff role*

How studies and interventions were promoted or offered by staff was highlighted as an issue affecting recruitment by some studies. For example: follow-up telephone contact 24-48 hours after initial study information was provided was found to improve slow recruitment rates (103); co-ordinating community service partners to generate referrals was required to facilitate recruitment (100). Galvin et al (100) suggested staff need training to try and ensure that screening protocols were followed. Goldsilver and Grunier (120) recommended that staff delivering the intervention need to play an active role in recruitment as this population did not come forward on their own initiative and that face-to-face contact and assessment rather than telephone contact was needed. Clare et al (20) emphasised the importance of practitioners considering people with dementia's and family members' readiness to make changes and motivation to address personal goals, during initial assessments for a cognitive rehabilitation intervention. Marshall et al (107) found that memory service nurses had considered potential participants overall physical and mental health before approaching them about the study alongside formal study screening criteria they had been instructed to apply.

Theme 4: *Key role of family members*

The key role of family members in facilitating participation in these interventions was clear in many studies. The majority of interventions required participation of a family member alongside a person with dementia, so if the family member was unable to participate nor would a person with dementia be able to. Ill health of family members were often cited as reasons for exclusion, declining to participate, withdrawal, poor attendance or adherence. The limited availability of working family carers was an issue reported as affecting recruitment in one study (121). Carer stress was cited as a reason for drop-out or limited engagement in some studies (113,116). Milders et al (116) reported this was because the person with dementia found the assessments too stressful or because the caregivers found it difficult or stressful to motivate their relative with dementia to engage in activities as part the cognitive stimulation intervention delivered by carers. Voight-Radloff et al (113) reported carer stress as reason for drop-out from an RCT of an occupational therapy intervention but further explanations about this were not reported. Also Woods et al (110) reported examples of carers withdrawing people with dementia from joint reminiscence groups, despite the person with dementia enjoying the groups. Orgeta et al (109) and Woods et al (110) questioned whether the responsibility placed on family members to participate in or deliver part of their study interventions may have contributed to carer stress or explained declining to participate initially as well as drop-out or poor attendance.

Reports of qualitative interviews undertaken with dyads or people with dementia alone to examine acceptability or expectations for interventions also highlighted the important role played by family members. Family members, as well as people with dementia, valuing the aims of the intervention, such as promotion of independence or social support were found to have encouraged uptake and engagement (103,117).

Theme 5: *Dementia related characteristics*

Some reasons for exclusion, declining to participate or limited engagement were related to characteristics or behaviours connected to the experience of living with dementia. Often reasons for exclusion were stated as due to diagnostic or severity criteria, but further explanations of this were not reported. Some other reasons reported for exclusions or declining also related to the experience of dementia. For example: Cheston and Howells (106) and Cheston et al (105) required people with dementia to demonstrate some awareness of their memory difficulties to participate in group psychotherapy or a 'Living well with dementia' group; 'being unaware of their diagnosis' (110) and 'denial or lack of insight into their illness' (120) were reported as reasons for exclusion or declining. Orgeta et al (109) reported some people with dementia becoming distressed and family not discussing dementia as reasons for declining participation. Gitlin et al (99) reported extreme aggression

or refusing to sign consent as reasons for ineligibility. Voight-Radloff et al (113) reported in their study occupational therapists had to rate certain aspects of treatment delivery as 'hindering delivery of treatment' 'neutral' or 'facilitating'. Some cases were rated as 'hindering delivery of treatment', which included the person with dementia's cooperation, daily changing mental capacity, collaboration with carer and acceptance of adaptations/suggestions. This suggests that at least some of the people with dementia and carers for whom these ratings were given demonstrated changing mental capacity at times, or, were unwilling or unable to cooperate with suggested activities, affecting ability to participate. Holthoff et al (114) reported some potentially eligible dyads declined participation in a physical exercise intervention because the person with dementia would not likely adhere to the protocol. Marshall et al (107) reported a reluctance to meet others with dementia was one reason for declining to participate in a 'Living well with Dementia' group intervention.

In contrast, studies which had interviewed people with dementia and family members (34,103,117) indicated that personal experience of living with dementia had facilitated uptake of interventions. This was because participants wanted support to cope with the impact of dementia on their lives (34,103,117).

2.12 Discussion

This review identified only one study explicitly addressing uptake of interventions and that was my own (34). It appeared that data about how many people offered interventions decline, drop out or are not eligible to participate may be collected but further examination of why is rare. Why people may accept or reject an intervention initially does not appear to have been explored within studies offering interventions to people with mild to moderate dementia.

Further, although several studies reported numbers of exclusions of potentially eligible people, those who declined to participate or drop-outs, it was often unclear whose views were being represented as the methods by which this data was gathered was not reported. Thus often it was not possible to know whether reasons given (for declining, being excluded or dropping out) had been reported by people with dementia, their family members or both people. Also whether such responses had been noted verbatim and then coded for analysis or fitted into a priori codes required for study data management processes was unclear.

In those studies reporting dyad interviews there was also limited reporting about methods used for joint interviews with people with dementia and family members together (for example (20,117)). This may have been because the main focus of the papers was effectiveness of interventions or potential feasibility, rather than full reporting of the participant experience. Keogh et al (14) did not include papers predominately about

experiences of interventions and so such papers were not included in this review. Reflective discussion about the challenges of carrying out joint interviews or of contacting people with dementia directly to discuss intervention and study participation or methods used to elicit the perspectives of people with dementia themselves on potential participation were absent.

This review has some limitations. Limitations of Keogh et al.'s (14) original search strategy of course extend to this review. Some relevant studies may not have been identified given the lack of a consistent terminology for psychosocial interventions, early or mild to moderate dementia and community living. For example, Keogh et al (14) used the terms 'mild' or 'newly' and 'home dwelling'. Thus papers using other terms for these words (in the database fields searched) would not have been identified. Keogh et al (14) also noted difficulties with applying their inclusion criteria as there was a lack of clarity in some papers about the stage of dementia or setting in which intervention was delivered. Thus they inferred whether or not some populations sampled met their criteria. The way that stage of dementia is assessed varied across studies and some did not report how severity was assessed. I tried to overcome this last issue by excluding those studies which did not offer enough information about samples for me to judge whether they included my target population.

It was not possible to duplicate and update the searches run by Keogh et al (14) due to difficulties translating the published search strategy across different databases and limited resources. However when I contacted the lead author, she felt confident that she had identified most of the relevant literature given her own and other authors' knowledge about current psychosocial intervention research.

Finally, findings from the research studies included in this review may not transfer to how people may respond to intervention offers in practice. Given this I trialled searches to identify literature about interventions in practice, but the practice literature I identified was not focused on psychosocial interventions for people with early dementia, living in the community. Although I did identify some studies reporting services early in the post-diagnosis pathway, family members were the research participants, not people with dementia and these were not focused on uptake of psychosocial interventions (for example, (67,124)). There may be several differences between how interventions are delivered in practice and in research studies affecting the transferability of findings. It may be standardised assessments of cognition, capacity to participate, dementia severity or ability to participate in outcome measures may not be required in the same way for practice settings as for research studies. In practice, assessment of suitability to participate in an intervention may rely more on clinician judgment than, or as well as, screening protocols. Exclusion criteria for certain co-morbidities or medications may be less likely to be considered in

practice compared to research studies. Also interventions designed for people with early or mild to moderate dementia may be offered to people more severely affected by dementia in practice. This may be because capacity to decide about participation and formally documenting signed informed consent may not be required in the same way for practice settings as for a research study. Also, uptake in practice could be more likely if the perceived burden of participation is regarded as manageable, compared to research, for example involving less burdensome outcome measures or study visits. Also, potential participants may know and trust practitioners offering interventions, compared to researchers. The primary research presented in Chapters 4 and 5 unusually and uniquely, in contrast with the evidence identified in this review offers perspectives gained from interviewing people with dementia and family members who were offered interventions as part of usual practice, rather than as part of research studies.

Completing this review confirmed that there is little research or understanding about what may influence acceptance or rejection of psychosocial interventions by people with mild-moderate dementia and their family members. This is a significant omission given the push for post-diagnostic care and support within services. However the themes identified from the studies included in this review, alongside findings from my empirical work (Chapters 4-6) informed the framework summarising influences on acceptance or rejection of psychosocial interventions (Chapter 7, Figure 7.1).

2.13 How findings from this review informed the proposed framework of influences on acceptance or rejection of psychosocial interventions

The key findings from this review were used to help develop the proposed framework of influences on acceptance or rejection of psychosocial interventions (Chapter 7 Section 7.4) were that influences on people with dementia accepting or rejecting interventions may be:

- Characteristics related to dementia
- Influence of family members and their ability to support people with dementia to attend
- The experience of living with dementia
- Co-morbidities, personal social living circumstances
- The role of staff and services providing interventions

CHAPTER SUMMARY

This chapter presented two literature reviews undertaken to inform this doctoral research. The first was an initial scoping review using systematic methods completed in 2016. The second, main review was completed in 2019. This involved a review of recent evidence about acceptance or rejection of psychosocial interventions. This main review informed the development of framework summarising influences on acceptance and rejection of psychosocial interventions, alongside the findings from my own research. Next, Chapters 3-6 present the main study and phase 2 of this PhD research.

Chapter 3 Methods

This chapter presents how this research was conducted. First it outlines my methodological stance. Second, the settings from which I recruited participants are described. Third, the methods used to sample, recruit and interview people with dementia, family members and staff are explained. Fourth, how the data was analysed thematically is presented, including triangulation to enhance depth of analysis and interpretation of findings. Finally, how I sought public and patient involvement, my publication and dissemination plans are then presented.

3.1 Methodology

As the introduction (Chapter 1) and scoping review (Chapter 2) indicated, the topic of uptake of psychosocial interventions by people with early dementia is under researched. Therefore, using a qualitative methodology to explore perspectives, views and experiences about this was appropriate (95,125,126). Further, the choices I made about how to carry out this research were related to my ontological and epistemological stance.

3.1.1 Ontological position

My ontological position is perhaps best expressed as 'subtle realism' as described by Hammersley (p.43 (127)). Hammersley (127) describes the social world as accessed through respondent's interpretations which are then in turn further interpreted by the researcher. This position enables a pragmatic stance and it is suitable given that the phenomenon of dementia is 'real': it is not entirely socially constructed; it involves a physical process of neurological degeneration. That is, dementia exists independently of our representations of it, yet our 'understandings' of it are only accessible through individual meanings and experiences. My ontological position is also aligned with Ormston et al's (128) approach:

> *"...we see reality as something that exists independently of those who observe it but it is only accessible through the perceptions and interpretations of individuals. We recognise the critical importance of participants own interpretations of the issues researched and believe that their varying vantage points will yield different types of understanding."* (p.21)

As multiple perspectives are valued and fundamental to this approach, I wanted to capture perspectives from people living with dementia, family members and staff who worked with these people. I believed that involving these different groups of participants, with their different perspectives and experiences, would contribute to a richer understanding of the

topic, as all are involved with the delivery and uptake of psychosocial interventions after diagnosis.

3.1.2 Epistemological perspective

My epistemological perspective is interpretivist and constructivist (95,126). As Ormston et al (128) summarise, this perspective means to me that:

> *"...social reality cannot be captured or portrayed accurately, because there are different (and possibly competing) perceptions and understandings."* (p.12)

From this epistemological perspective, objective research is not possible. However, aiming for transparency about the research process, assumptions, potential biases and trying to represent participants' meanings faithfully is possible (129).

3.2 Methods

3.2.1. Choice of interviews as a data collection method

I chose to undertake interviews for several reasons. Firstly, as uptake of psychosocial interventions was under-researched area (see Chapter 2) seeking the views and accounts directly from people with dementia was an important and suitable first step to identify key issues within this topic, to inform an understanding based on the accounts from people with dementia themselves. There is a limited body of research that directly asks people living with dementia about their experiences and the importance of gaining accounts directly from people with dementia themselves about issues which affect them is acknowledged as essential (25,47,130). The phrase 'nothing about us? without us', often used by dementia advocacy organisations also indicates that involving people with dementia directly in research and asking them to share their experiences is vital and ethical (for example, (131,132)). Secondly, when beginning this main phase of the research in 2016, it was unclear what kinds of interventions were being offered to people with dementia in practice, despite some literature reviews summarising the effectiveness or different types of interventions (for example, (12,13)). Thus, I wanted to ask people directly about what interventions they had been offered. Thirdly, I valued interviews as a method that could help me understand the experiences of and the phenomena of acceptance and rejection of interventions from the perspective of people with dementia themselves (both interviewed alone or supported by family members in joint interviews), then interpreted by myself as the researcher. Semi-structured interviews using an indicative, not fixed, topic guide, adapted to the person I was interviewing offered a way to try and understand participants' experiences and views in depth.

However, as Kvale and Brinkman (133) express with metaphor, there are different ways to understand the nature and meaning of interview interactions. For example, a positivist or post-positive social science position regards knowledge as a given:

"knowledge is understood as buried metal and the interviewer is a miner who unearths the valuable metal...the interviewer digs out nuggets of knowledge ...unpolluted by any leading questions" (133) (p.48)

For others, such as myself, more closely aligned within a constructivist model, Kvale and Brinkman (133) suggest the metaphor of a traveller:

"The interviewer-traveller, in line with the original Latin meaning of conversation as 'wandering together with' walks along with the local inhabitants asking questions and encouraging them to tell their own stories of their lived world..." (133) (p.48)

I find this metaphor helpful in highlighting the joint nature of the interaction and data created in interviews, particularly for people with dementia who may need support from another person to engage in an interview (see Section 3.2.5). However, adopting an extreme post-modem position may deny the possibility of participants sharing their experiences and views with researchers (134). Thus, I took a pragmatic stance to understand the nature of interviews I was going to undertake for this research; acknowledging interviews as interactions between participants and myself, the interactions shaping the form and features of the data generated. This data could help illuminate issues affecting acceptance and rejection of interventions.

Further, my own experience of working with people with mild-to-moderate dementia on the VALID research programme (see Chapter 1 Section 1.2) indicated that many people with early dementia were likely be able to engage in interviews, particularly if methods were employed to support them as outlined in Section 3.4 below and as suggested by various researchers (for example, (25,130,135)). Other researchers had clearly demonstrated interviewing people with early dementia was possible and desirable ((for example, (25,28,71)).

Interviews with staff also offered one way of trying to understand more about the context within which psychosocial interventions are provided and discussed with people affected by dementia, from staff's perspectives. This was important as I thought it likely that people who declined interventions would also decline to participate in this research. I considered staff may be able to discuss their experiences of people declining interventions.

However, before choosing to conduct interviews, I recognised as Silverman (95) contends, that interviews are only one way of:

"....slicing the cake' and that other approaches, using other forms of data may not be directly competitive" (95) (p.49).

I recognise that people may not attach single meanings to their experiences and that there are likely multiple meanings presented by what participants may say to a researcher, what they may say to others such as health professionals or members of their family.

Therefore, initially I considered both interviews and observations as methods that could potentially help to collectively meet my research aim and objectives (see Chapter 1, Section 1.6). As I weighed up the advantages and disadvantages of observational and interview methods, I was guided by my ontological and epistemological perspective, which leads me to believe there is no one objective truth to be observed or accessed. I considered that both observational methods and interviewing people with dementia and staff offered valuable ways to try and understand the phenomenon of acceptance and rejection of interventions, but would obtain different types of data and so different types of understanding.

Various researchers (for example, (95,136,137) suggest qualitative researchers consider the merit of data that occur 'naturally' (i.e. without the intervention of a researcher) to thereby accessing what people are routinely up to, without being asked by researchers. Observational methods can be suitable for research topics that involve complex interactions or processes which it would be difficult to describe accurately or fully, subconscious or instinctive interactions or behaviours that are so 'every day' or 'normal' that people may find hard to convey in words (136). Observational or ethnographic methods involve researchers immersing themselves in a social situation to collect 'naturalistic' data in a pragmatic, reflexive and emergent way (137,138). This typically requires lengthy participation in the everyday life of a chosen setting, by observing interactions and behaviour, but also by talking to the members of the social world being studied (138).

How people with dementia and family members were offered interventions in different practice settings and how they responded appeared to be a complex social interaction. I questioned if people with dementia, family members and staff may find it difficult to describe or recall interactions about interventions in interviews. Given this, observational methods did appear to offer a way to illuminate and understand these issues and some potential advantages. However, I was unsure if using observational methods were feasible. Also such methods would not offer the opportunity to understand and interpret people with dementia's own accounts in depth; I wanted to know what people with dementia thought about the interventions they had been offered as first step in exploring this topic.

Using observational methods requires making decisions about what to observe, where and how. This includes selection of sites, behaviours and activities to be observed, the

interactional setting and time frames (136). I considered possible settings where psychosocial interventions were offered. I also considered whether I would be able to conduct in-situ interviews within potential fieldwork settings, as other ethnographic studies observing people with dementia and staff have done (139–142). A significant preparatory phase would have been required to identify potential sites, a rationale for their selection and familiarising myself with the practices of that setting (for example, when and where interventions are offered and by who) so that I could make decisions about how to collect data, when and where. Further, it was likely that decisions about interventions would be considered by people with dementia and families after interactions with professionals, and over time, so it would not be possible to observe all such moments.

Possible settings to observe could have included NHS memory services, other types of NHS services or different non-statutory organisations offering interventions in the community aimed at people with dementia. Deciding a criterion to select settings would have been challenging given provision of psychosocial interventions and post diagnostic support is variable across England (5,10). I would have needed support from the relevant organisations and ethical approvals to observe a range of actions and behaviours at selected sites. I would have needed to explain the consent process with all those I might observe. This could have potentially included not only people with dementia, family members and staff offering interventions but also other staff and members of the public. I may have been able to negotiate gaining verbal consent, as Clisset al (140) report or obtaining signed consent, as Featherstone et al (139) report. 'Opt-outs' offered by staff or via notices in spaces I was observing was another possibility. However, I unsure of being able persuade sites to participate, particularly within the timeframe needed for this doctoral research. As Pope acknowledges (138) it can be difficult for researchers to identify the particular individuals within organisations who can grant the permissions needed for such studies.

Reports of ethnographic studies conducted with people with dementia (139–143) indicated to me the time and resources needed to set up, carry out and analyse observational research. Such methods can generate huge amounts of recorded data. I also attended a course entitled 'Doing ethnography' (University of Nottingham, 2016) and a discussion group run by and for ScHARR researchers using ethnographic methods. These opportunities enabled me to talk to researchers with experience of conducting ethnographies in health service settings and further led me to understand the time intensive nature of set-up, fieldwork and analysis required of such studies.

I also needed to consider the effect of myself as an observer on the data and potential effects of my observations on the observed behaviours and interactions, sometimes referred

to as the 'Hawthorne effect', which is unclear (144). Whether my position would be that of a complete observer or an observer as participant (145) would also have needed consideration and negotiation for each setting.

After weighing up the challenges and advantages of observational methods I felt such methods would not offer me the opportunity to interview people with dementia in-depth about their experiences and views of interventions they had been offered. Also I was concerned about achieving the level of familiarisation and initial access needed to inform decisions required about what, when and how to observe. This did not appear feasible with the time and limited resources I had available.

However, Nygård (135) suggests that using a combination of observations and adapted interviews may facilitate people with dementia to engage in research and researchers to access the experiences of people with dementia. Nygård (135) suggests this is important as that interviews require communication and verbal skills, yet these are skills often affected early in the course of dementia. Silverman (95) also discusses combining observational methods with semi-structured interviews, completed outside of a fieldwork observational setting. Such an approach did appeal to me as offering a multidimensional understanding, using different methods. However, as Silverman (95) emphasises, the disadvantages of such a multiple methods approach are the time and resources required to gather and analyse such multiple data sets. He suggests the danger is that one or other of the data sets will be under-analysed. I was concerned that if I attempted to combine both observations and interviews within the time and resources I had available, I risked this outcome.

Using interview methods offered the opportunity to hear in detail from people with dementia themselves and for me to interpret these accounts as a first step in exploring this topic. I also considered the demand interview participation placed on participants, how I could access participants and secure ethical and governance permissions. It appeared to me that interviews might be perceived as less burdensome to people with dementia, families and potential sites by potential collaborators, than observational methods. Interview methods also appeared achievable within the time and resources I had available. Thus I decided conducting interviews was a worthwhile method for understanding influences on acceptance and rejection of interventions and that future studies using observational methods could perhaps be used to build on the findings obtained.

3.2.2 Reflexivity

Reflexivity is crucial within qualitative research (128). As Mason (146) contends, researchers need to demonstrate to others what led them to make the assertions they do. I acknowledge

that all research will be influenced by the researcher and that there is no completely 'neutral' or 'objective' knowledge (p.22). Further, as Mason (146) suggests, I conceptualise myself as:

> '…active and reflexive in the process of data generation and seek to examine this, rather than aspiring to be a neutral data collector…' (p.114-115)

Therefore I incorporated methods to help me reflect on my influence on the data throughout the research process. Regular academic supervision helped me to consider my assumptions and potential biases. I kept an anonymised research diary during the set up and recruitment process. I made field notes after all interviews which were transcribed with the rest of the interview. Field notes involved recording my observations, thoughts and feelings. For example: participants' body language, eye contact and their home environment; whether I felt I had elicited data relevant to the research question; how accounts given by the person with dementia and a family member during joint interviews appeared similar or different; how the person with dementia had engaged and communicated during solo and joint interviews. These notes and reflections were coded during analysis to help interpretation.

Given the need to be reflexive within qualitative research, it is important to explain my own position and background as this will have impacted on the way I conducted this research and data obtained. I discuss this in Chapter 7 (Section 7.2). I worked as an occupational therapist in the NHS for 13 years before completing an MSc in Clinical Research in 2012. The majority of my clinical experience involved working in a community rehabilitation team for people with brain injuries with mostly cognitive and behavioural difficulties. I have worked as a researcher since 2013. I remain a state registered occupational therapist.

3.2.3 Ethical approval
I obtained NHS ethical approval from North West-Greater Manchester East Research Ethics Committee on 5 September 2017 to recruit and interview people with dementia and family members and staff via the NHS (REC reference: 17/NW/0414, Appendix 3.1). I also gained HRA and local governance approvals.

3.2.4 Description of recruitment and fieldwork settings
This research involved recruiting participants from two different geographical locations, hereafter referred to as location 1 and location 2.

Location 1 was a town, with surrounding villages, some rural areas and a population of approximately 257,280. Location 2 was a city, with surrounding areas, including some

outlying villages and a population of approximately 518,000. Within each location post-diagnostic support services were offered by NHS services and included a memory service, hereafter referred to as Memory Service 1 and Memory Service 2.

Both memory services were staffed by multi-disciplinary teams including, nurses, occupational therapists, and support workers or nursing assistants. Memory Service 1 worked with psychologists and consultants based in other older people's mental health services, although in the same building. Memory Service 2 had psychologists a consultant and doctors as part of the memory services staff team. Types of support and interventions offered were different in each location, as observed by the memory services accreditation programme (MSNAP) and Department of Health who recognise that the way diagnostic and post-diagnostic services are provided varies across England (5,10). Local branches of the Alzheimer's Society also operated within each location to support people affected by dementia and both offered psychosocial interventions. I do not claim that the memory services and locations from which participants were drawn are representative of other dementia or memory services. Rather, I aimed to describe my findings in depth, so that, as Mason (146) suggests:

> *'....qualitative researchers can make some claims for the wider resonance or generalisations based on the rigour of [your] analysis....' (p.245)*

By recruiting participants from two locations I aimed to examine how people with early dementia discussed experiences of being offered psychosocial interventions in different contexts.

Memory Service 1 (location 1): Memory Service 1 was part of an NHS Foundation Trust providing mental health, learning disability and community services across an area that included location 1 as well as other geographical areas. For the rest of the geographical area served by this NHS Trust, diagnosis and post-diagnostic support was provided by community mental health teams for older people.

Memory Service 2 (location 2): Memory Service 2 was part of an NHS Foundation Trust providing mental health, learning disability, community and some primary care services. This memory service was situated in a building on a large general hospital site beside an in-patient mental health unit.

Local branch of Alzheimer's Society (location 2): The Alzheimer's Society is a national care and research charity for people affected by dementia. It has local branches across the UK. The kinds of services offered may differ according to location and resources. This branch of the Alzheimer's Society offered some intervention groups from their building in the

community or other community locations. Their staff also visited people with dementia and families at home or made contact by telephone.

3.2.4 Rationale for choosing these settings

It is recognised that people with dementia can be hard to reach and recruit to research studies (23,147,148). Thus, I chose these settings because I could negotiate access to potential participants and begin recruitment within the timeframe needed. Also, the geographic locations meant I could travel to participant homes or sites required. After making initial enquiries with the NHS trust in location 1 and the manager of Memory Service 1, I secured their support to recruit participants from Memory Service 1. My initial attempts to make links and gain access to managers and staff in order to recruit participants from other dementia services in location 1, such as community health teams, proved unproductive. Given this I decided to invest most of my time and resources into promoting the study at Memory Services 1.

In addition, my own experience of recruiting people with dementia from Memory Service 2, as part of the VALID research programme (see Chapter 1 Section 1.2) indicated that negotiating access and recruiting within the timeframe I had allocated for recruitment would be difficult given the demands on that service. I also knew they would prioritise recruitment to another dementia research study also seeking people with early dementia to participate, running at that time.

3.2.5 Rationale for offering solo or joint interviews to people with dementia

How best to involve people with dementia in qualitative interviews needs consideration (27,130,135). In this research, two types of face-to-face, semi-structured interview were offered:

1. **Solo interviews:** an interview conducted with the person with dementia alone was discussed and suggested if appropriate
2. **Joint interviews:** if the person with dementia and/or the family member did not feel a solo interview was appropriate, joint interviews were offered.

The decision to offer this choice of interviews was informed by other studies which described giving people with dementia a choice about whether they wished to have a family member with them (for example (82,84)). Giving this choice aimed to facilitate the participation of people with dementia who felt that they needed support from another person (82). It also allowed those who did not wish for this, or did not have a suitable family member available, to participate alone. If a person with dementia was experiencing verbal communication and recall difficulties, as might be expected (27,130,135) they or a family member may feel they

need support to participate in an interview. Nygård (135) suggests that using other people as a means of supporting the person with dementia can be appropriate, that these people can act as informants alongside the participant. Or, it could be personal preference to be interviewed alongside a family member.

I also recognised that family members can act as gate-keepers. My previous experience of recruiting people with dementia and carers to research (see Chapter 1 Section 1.2) echoed Cridland et al's (130) description of family members frequently being the ones to respond to study recruitment materials. Family members may be concerned that research involvement could be confrontational or uncomfortable and want to protect a person with dementia from potential distress (27,29,130). My intention was to treat such perspectives sensitively, whilst being transparent and explain why separate interviews were suggested; that sometimes it can be helpful for a person to talk without worrying about the impact of what they say on the family member, and in this research, I wanted to hear from people with dementia themselves. However, involving others alters the process of data collection and analysis as Nygård (135) and Murphy et al (25) highlight. Therefore, how I conducted and analysed joint interviews is presented in Sections 3.4.2 and 3.9.1.

3.3 Sampling and recruitment strategy: people with dementia and family members

My previous experience recruiting people with dementia and other research suggested people with dementia can be hard to access and recruit (23,147,148). Given this, seeking a convenience sample was the most feasible option for this research. The choice of a convenience sample was also partly because I considered that obtaining data saturation might not always be possible (149) and may have required more participants, time and resources than was feasible for this research. I aimed to sample and interview as many people as I could recruit who met the study criteria over a nine month period. At the outset I estimated this may be between 10-20 people with dementia.

Therefore my recruitment strategy involved the following:
1. NHS memory services: Memory Service 1 and 2.
2. The 'Join Dementia Research' online research register.
3. A local branch of the Alzheimer's Society in location 2 (hereafter referred to as the Alzheimer's Society).

Establishing suitability to participate
To be suitable to participate, people with dementia needed to:

➢ describe themselves, or others (such as family members or staff who knew them) needed to report them as having received a diagnosis of a dementia within the last two years and living with early dementia;

➢ be 65 years or older;

➢ be able and willing to take part in a one-to-one 'solo' interview, or a joint interview with a family member of their choice;

➢ have the capacity to consent to participate in the study;

➢ live in the community, in their own home or sheltered housing (but not in residential or nursing care)

Rationale for suitability criteria

I wanted to identify people whose experience of dementia at the time of interview, was such that they would potentially benefit from participating in psychosocial interventions and be able to consent to participate. I did not want to assess a 'stage' of dementia using a clinical rating scale as I wanted to privilege the accounts of people with dementia. Therefore I accepted self-report of early dementia, as Mountain and Craig reported doing in their study (84). My inclusion criteria also required people with dementia to be within two years post-diagnosis. This 'cut off' time after diagnosis was intended to decrease the chances of people who were not suitable to participate being identified and approached about the study. Yet, I also recognised that some people diagnosed within the last two years could be moderately or severely affected given that when people present for and obtain a diagnosis is variable. If people with dementia themselves were unable to recall when they had been diagnosed, I planned to seek their verbal consent to confirm the time since diagnosis with a family member or member of staff that knew them.

I focused on people who were over 65 years old because dementia is most common in this age range, affecting one in 14 of the population over 65 years (150) and literature about people diagnosed under 65 years dementia indicates these people have particular needs which merit consideration in their own right (151,152).

To be suitable to participate, family members needed to:

➢ be over 18 years old;

➢ be the person the person with dementia wished to have participating in a joint interview alongside them;

➢ have capacity to consent in the study;

➢ be able and willing to participate in a joint interview with the person with dementia

I did not recruit family members as a separate sub-sample to explore their own perspectives separately from people with dementia they supported, yet recognised they would voice their own their views during joint interviews with people living with dementia. Thus family members were only recruited to be interviewed alongside a person with dementia if the person with dementia wished for this; no interviews with family members alone were offered.

3.3.1. Recruitment process for Memory Services 1 and 2

The recruitment process for Memory Services 1 and 2 is summarised in Table 3.1 (see Appendices 3.2-3.9 for copies of recruitment materials).

Table 3.1 Recruitment process for Memory Services 1 and 2

Setting	Actions
	Identifying potential participants
Memory Service 1	Initial telephone interview with manager to identify what post-diagnostic support and psychosocial interventions were provided, staffing mix and to agree recruitment methods. These involved: 1. Manager emailed staff introducing the study and requesting staff identify potentially suitable people with dementia during their post-diagnosis and review appointments. 2. I also asked staff myself to identify potentially suitable people during post-diagnosis and review appointments myself, after meeting staff at the focus group.[1] 3. If people with dementia expressed interest, staff were asked to complete a 'permission to contact form' with them and offer a participant information sheet (PIS). 4. Prompt emails were sent to staff via the manager regularly during the recruitment period. 5. All recruitment materials were left in the clinic office for team meetings. 6. Flyers were placed in waiting areas. 7. I also attended cognitive stimulation therapy (CST) groups to promote the study. Those that expressed interest completed a 'permission to contact form' and were given a PIS.
Memory Service 2	1. Flyers were placed in waiting areas. 2. Research nurse planned to offer study information to potentially suitable people with whom she had contact with.
	Initial contact
Memory Service 1	1. Name given on 'permission to contact form' contacted by telephone (or email if this was the only contact detail given). 2. Telephone conversation to introduce and discuss the study with the person with dementia and family member if there was one. 3. Covering letter and PIS sent by post or email as preferred. 4. Telephone call to discuss participation a minimum of 24 hours after PIS received.
Memory Service 2	No potential participants with dementia were identified via Memory Service 2.
	Screening
Memory service 1	Demographic questionnaire completed by telephone with person with dementia or family member if needed, to establish suitability to participate.
	Arranging interview
Memory service 1	1. Interviews arranged at a time and place convenient to participants. 2. Confirmation of appointment letter sent with one page summary. 3. Reminder telephone call on day of interview and/or day before offered.

[1] A focus group was held with staff at Memory Service 1 before recruitment of people with dementia and family members started

3.3.2 Recruitment process for 'Join Dementia research'

Join Dementia Research (JDR) (https://www.joindementiaresearch.nihr.ac.uk) is a National Institute for Health Research (NIHR) internet based register designed to put researchers directly in touch with potential participants for dementia research. This includes people with

dementia themselves and family members or carers. This research was promoted on JDR using a lay summary, as required by JDR (see Appendix 3.10). JDR requires people with dementia to provide basic demographic and background information about themselves and a 'representative' (such as a family carer, relative or friend) in order to match them with potential research studies. People can state a preferred contact method and that researchers should contact the representative and not the person with dementia themselves. Providing date of diagnosis or severity of dementia was not a mandatory field to complete within the JDR registration process. Therefore I set filters within JDR to include:

- all those within a 10 mile radius of location 2 AND
- those who had stated mild dementia (terminology used by JDR) OR a date of diagnosis between Sept 2015-Sept 2017 OR this information was not included

This strategy was agreed with JDR to identify as many potentially suitable people as possible.

The initial contact process for JDR was as follows:

➢ People with dementia or their 'representative' were contacted using their preferred contact method (telephone, email or post).
➢ The PIS (Appendices 3.3 and 3.4) and covering letter (Appendix 3.9.1) were sent by post or email, or after initial telephone contact (depending on preferred contact method) if people were interested and suitable to participate.

3.3.3 Recruitment process via the Alzheimer's Society

After approximately two months of trying to recruit participants via memory services, I introduced an additional recruitment strategy. This was because I had received only three referrals from staff in Memory Services 1 and none from Memory Services 2. Therefore I also approached the Alzheimer's Society in location 2. I already had links with the manager of this branch through my former work role. Also, staff interviews and the focus group already completed indicated that people with early dementia attended interventions provided by the Alzheimer's Society and NHS staff often signposted people to the Alzheimer's Society for support. Therefore, approaching a local branch of the Alzheimer's Society was an appropriate way to try and recruit more participants. I did not have links with other branches of the Alzheimer's Society, for example, those in location 1, so focused my time and resources on the established links I had to develop this additional recruitment strategy. The Alzheimer's Society manager agreed that they would talk to staff about the study. Then, these staff would identify and talk to potentially suitable people with dementia about the study, most likely by telephone. If potential participants consented verbally, staff would pass their contact details to me in person by telephone.

The initial contact process for participants recruited via the Alzheimer's Society was as follows:

➢ I contacted potential participants by telephone.
➢ I completed the demographic questionnaire (Appendix 3.8) with them to ensure suitability to participate.
➢ The PIS (Appendix 3.3 and 3.4) and covering letter (Appendix 3.9) was sent if they expressed interest.
➢ Participants were asked to complete a 'permission to contact' form (Appendix 3.2) retrospectively at interview, given this was an ethical requirement and as reminder that they had given their consent to Alzheimer's Society staff for me to contact them.

The procedure for screening and arranging appointments for participants recruited via JDR and the Alzheimer's Society followed the same process as summarised in Table 3.1 above.

3.4 Data collection for people with dementia and family members

3.4.1 Before interviews
Establishing capacity to consent to this research
Completing a capacity assessment (Appendix 3.11) was designed to help me establish the components of capacity needed to make a decision about participating in this study, according to the Mental Capacity Act, 2005. That is, that the person with dementia was able to:

1. **Understand** the information I told them that was relevant to their decision about participation.
2. **Retain** the information long enough to make a decision about participation.
3. **Weigh up** the information provided to make decision about participation.
4. **Communicate** their decision about participation.

A one-off act of obtaining consent may be inadequate for some people with dementia (153,154). This can occur particularly if people with dementia experience their function, cognition, or well-being as better on some days or better at some times, than others. Several authors also highlight the importance of building in time to talk informally, to try and put people with dementia at ease, building rapport and as a basis for establishing consent (29,130,153). Dewing's (154) model of process consent outlines the importance of preparation and background, establishing a basis for consent, gaining initial consent, on-going consent, then of monitoring, feedback and support. To prepare, gain background information and establish a basis for consent I planned the following:

- To spend time during initial contact talking and getting to know the person with dementia, and if appropriate the family member; gain background information via the demographic questionnaire (for example about previous occupation) which could be used to establish rapport
- To explain the research and the interview, what was involved for them and ask if they would like to continue speaking to me; to ask how they might find being interviewed and if they had any specific needs to consider, such as sight or hearing difficulties, best times of day, or health issues

Signed, informed consent was obtained for all participants before the interview started (Appendices 3.12 and 3.13). Once participants had consented I checked again they were happy to proceed with the interview.

Interviews were planned to last up to one hour but I was prepared for them to take less time, particularly perhaps for the solo interviews with people with dementia. This was because people with dementia's abilities to concentrate, fatigue or communicate verbally would likely be variable. Murphy et al (25) noted that even for people with dementia able to participate in interviews, their response to questions can be short. All interviews were audio-recorded using an encrypted digital recorder.

3.4.2 During interviews

To try and maintain ongoing consent, I reminded people they could take a break any time and did not have to answer any questions they did not wish to at the start of interviews.

An indicative topic guide was used to guide interviews (Appendix 3.14). This indicative topic guide was based on the findings from phase 1 of this PhD and developed with my PhD supervisors. This was an indicative guide, so not exactly the same questions were asked of each person as it is important for a researcher interviewing people with dementia to be prepared to follow the respondent (135). I needed to respond to how people with dementia responded to the questions and talked about the topics. For example, if a person had difficulty recalling details of interventions I was prepared to focus less on this and more on personal interests, how they wished to spend their time, whether they saw a role for services to support them, what they thought services should offer and what they might say to others with dementia about how to live as well as possible. Interviews aimed to draw upon peoples' own experiences and views to explore the topics summarised in Box 3.1.

> **Box 3.1 Summary of indicative topic guide questions**
> ➤ (Warm up) How people liked spending time, previous occupations.
> ➤ How life has been since diagnosis.
> ➤ Experience and feelings about support and services offered after diagnosis.
> ➤ Any support or services or intervention offers recalled.
> ➤ Types of interventions attended or declined.
> ➤ Possible reasons for uptake or declining offers.
> ➤ Possible influence of staff, content of intervention or how life was at time of uptake or rejection.
> ➤ What else people would have liked to been offered by services, if anything (prompts given if needed for example: support to carry on with activities or interests they had told me about, physical exercise, mental stimulation, meeting new people).
> ➤ When and where should interventions be offered?
> ➤ What advice would people give other people living with dementia recently diagnosed about living as well as possible with dementia, or responding to intervention offers?

Supporting people with dementia to engage in interviews

To support people with dementia to participate in solo and joint interviews I drew upon existing literature (for example (27,82,84,130,135). In a review of strategies to maximise the inclusion of people with dementia in qualitative research, Murphy et al (25) highlight the importance of maximising responses by taking time, building a relationship and being flexible. Hellström et al (27) describe the need to create a safe environment, build trust and rapport. Nygård (135) advises that allowing time is vital and interviewers must be prepared to adapt the length of each interview. I prepared to conduct interviews over more than one session if indicated. I was also prepared to include pauses and related small talk, allowing participants to rest, be patient listening and await participants own expressions (135). If participants with dementia lose track of the conversation, Nygård (135) suggests repetition of the topic, repeating what the informant just said or slight changes in wording, which I planned to do. I considered that the traditional semi-structured interview technique of asking open ended questions (134) may not always be appropriate, as Nygård (135) also recognises. This is because of the challenges people with dementia can face when trying to communicate (135,155). Therefore, I prepared to offer a range of responses and had key topic guide questions typed up in large font, spaced out well, to use as written prompts if needed. I asked if such strategies may be helpful and used my judgement in whether to try these methods. I also verbally summarised what participants said as the interview progressed as a way to support people with dementia track the conversation.

In keeping with methods for process consent (154) that indicate the importance of feedback and support, and as people with dementia may need extra time to process information and

articulate a response, I always offered reassurance that their contribution was valuable and that there was no need to hurry with responses.

I planned time to just talk before beginning the interview, so that people could start to feel comfortable with me, building, also enabling me to gain some understanding of how people communicated, to try and identify a person's expressive language capacity (156). Murphy et al (25) report engaging in much 'chit chat' prior to interview, to set the scene, ensure the person with dementia was comfortable and to gauge how best to engage the person with dementia in the interview. A one page summary (Appendix 3.7) sent in advance aimed to enable participants to process information about the study in advance if they wished. It could also be used to help orientate them during interview.

Murphy et al (25) also reported reviewing documentation, observational and context work enabled interviewers in their research to use prompts or cues within interviews with people with dementia. Interviews I held with the manager of Memory Services 1, some staff and the staff focus group were conducted before interviews with people with dementia. These interviews enabled me to identify the kinds of services and interventions available in the locations in which participants lived. This meant I was aware of the kinds of interventions participants may have been offered, I could discuss these in interviews or prompt verbally if needed. I also took photographs of both memory services' waiting areas and of some staff, to use as visual prompts to stimulate conversation with people with dementia if needed.

I found that the existing literature offered limited practical recommendations on how to try and ensure a family member's account did not dominate during joint interviews. Given this, during joint interviews I planned to sit where I could maintain eye contact with the person with dementia, turn my body towards them and direct questions to each person separately, rather than jointly. Before interviews, I tried to discuss with both people how we could conduct the interview and that I would start by asking the person with dementia questions first.

At the end of interviews I also offered to leave a stamped addressed envelope and some paper to allow participants to respond to anything they had forgotten during the interview (29), if they wished. This was mostly declined and I received no responses from those who did accept this.

The importance of paying attention throughout interviews to verbal and non-verbal communication to identify if people with dementia become distressed or fatigued is

recommended as another way of maintaining ongoing consent and monitoring (154). If participants became upset, I planned to suggest we stop and take a break, carry on another day, or that they could withdraw completely. Also, I had planned that if a person with dementia was unable to participate in an interview as planned I would offer a written summary as a reminder of what had happened. For this reason I designed a 'calling card' with a photograph of myself and space for brief notes (Appendix 3.15).

3.4.3 After interviews

I recognised the importance of acknowledging the contribution made by the person with dementia and of closing interviews on a positive note (25,29). Therefore, at the end of interviews I made clear verbally how much I valued participants' contribution and spent some time just talking to people, for example about what they had planned for the rest of the day or anything else they wanted to talk about. I also reiterated anonymity and confidentiality. A thank you letter (Appendix 3.16) and a copy of their consent form was sent to participants. A summary of key findings was also sent to all participants who requested this (Appendix 3.25).

3.4.4 Managing potential risks

I considered whether harm or embarrassment could be caused to participants. Although this was unlikely, I wanted to minimise potential stress, give positive feedback, observe and respond to signs of fatigue or distress, as outlined above.

If a participant disclosed that they may harm themselves or others, or if family members felt that health and safety of the person they supported were at risk, I had a plan in place. This involved:
  ➢ Telling participants that I would need to share this information with my supervisors who may suggest I inform the local memory services or GP.
  ➢ Advise participants to contact their GP or memory services.
I also adhered to the University of Sheffield Lone working policy, informing a 'buddy' of all my visits to participants' homes.

3.5 Sampling and recruitment strategy: staff participants

I aimed to obtain a convenience sample of staff working in the NHS or other dementia services providing referring or signposting to psychosocial interventions for people diagnosed with early dementia living in the community. I considered that recruiting staff may present a challenge given managers would act as gatekeepers to other staff and may feel

that staff taking time away from front-line service provision to participate in interviews was not possible. I was unable to compensate services for staff time or say that participation would lead to direct benefits for their service or service users, other than contributing to research in this field. Therefore, seeking a convenience sample of staff was appropriate for this research. I estimated this sample may include up to approximately 10 staff, given the time and resources available for recruitment.

Within the convenience sample achieved I sought and gained some variation. Managers, intervention providers and referrers, and different professional groups such as a doctor, nurses, a psychologist, occupational therapists and support workers, working at different levels of seniority were recruited.

Recruiting staff from Memory Services 1

I approached the manager of Memory Services 1 as the gatekeeper to staff providing services. I completed an initial interview by telephone to help me gain information about the service and plan recruitment. I gained verbal consent for this (Appendix 3.17) and used a brief indicative topic guide (Appendix 3.18) to find out:

- What if any psychosocial interventions are offered?
- At what point/s after diagnosis?
- Which staff provide, refer or sign post to these interventions?

It was agreed that I could invite staff to participate by sending emails via the manager (Appendix 3.19). The manager also gave me direct contact details to approach a clinical psychologist and two doctors who worked with Memory Services 1 and were involved in post-diagnostic support provision, but were not considered part of the core memory service team.

We also discussed methods of data collection. I suggested that I could offer staff telephone semi-structured interviews, face- to-face or a focus group interview. The manager agreed that memory services staff could participate in a focus group interview, rather than individual interviews, to minimise service disruption. I then sent a PIS (Appendix 3.20) via the manager, by email, to all staff in Memory Service 1 several weeks before the focus group was due to take place. The focus group was offered over an extended lunch break on a date the manager suggested as most convenient for staff and the service.

As this recruitment strategy did not yield a sufficiently varied sample, I then approached other staff.

Recruiting other NHS staff

I recruited one occupational therapist who had worked in a memory service previously in order to pilot the staff topic guide. I knew this person personally.

When I was unable to contact the two doctors working with Memory Service 1, I approached a doctor who worked with Memory Service 2 to ask if they were willing to participate.

All these potential participants were sent a PIS (Appendix 3.20). I telephoned or emailed after a minimum of 24 hours had passed to discuss participation. These staff were offered a choice of telephone or face-to-face interview at dates and time convenient to them.

Recruiting staff from the Alzheimer's Society

I approached the manager at the local branch of the Alzheimer's Society about whether I could interview any staff there. The manager suggested I interview both themselves and a support worker together in a joint interview.

Rationale for offering different types of interviews

Offering a choice of data collection methods to staff was necessary to minimise the time demand placed on staff providing services and to facilitate recruitment. Whilst the decision to complete a focus group was initially pragmatic, it also offered an opportunity to gain insight into participants' perspectives and experiences, stimulated by group discussion and interaction to generate the data (157). I also saw value in collecting data using different methods which could enhance my analysis and facilitate data triangulation (158). The individual face-to-face-interviews allowed staff participants to talk in more detail. The telephone interviews allowed me to gain information and personal views from participants that otherwise may not have felt able to participate.

3.6 Data collection for staff participants

For the focus group and individual face-to-face interviews signed informed consent was taken (Appendix 3.21) at the time of interview. When telephone interviews were conducted verbal informed consent was taken and this was recorded on the consent form. Copies of the consent form were given or sent to all participants.

An indicative topic guide (Appendix 3.22) was based on phase 1 of this PhD research, developed with my supervisors and piloted on the first staff participant. I included the data obtained from this interview in the analysis. As this was an indicative topic guide it was tailored to the type of interview being conducted and adapted for use within the focus group. The interviews and focus group drew upon staff experience and views to explore:

(1) Experience of signposting, referring to or providing psychosocial interventions to people with early dementia.

(2) Influences on people with dementia's uptake or rejection of such interventions.

(3) Types of support or interventions they consider might be appropriate.

All staff interviews and the focus group were audio-recorded, except the first interview with the memory services manager, for which notes were taken.

3.7 Data protection and management

Personal contact details for participants who consented to be invited to and subsequently participated in this study and copies of correspondence were stored on a password protected computer. These computer files are password protected and stored on a password protected and restricted access folder on the secure server within the University of Sheffield. When a laptop was used it was encrypted, to provide additional protection of personal data. Personal contact details for those who declined to participate were deleted. My notes about reasons given for declining were anonymised so that I could examine how many people declined and why.

A master file that associates a named participant and their contact details and a unique study identification number (study ID) was created. This study ID was used on interview transcripts, analysis files, consent forms, demographic questionnaires and notes from the interview with a manager. In this way someone outside the project would not be able to identify an individual participant. The master file is held on a password protected and restricted access folder on the secure server of the University of Sheffield. Only myself and one supervisor are able to access this data.

3.8 Anonymity and confidentiality

Transcripts from all interviews were anonymised. Personal details which could identify participants were anonymised or deleted within the transcripts. Quotations from transcripts were anonymised using study ID numbers. The professional transcriber employed was a University of Sheffield staff who had completed information governance and data protection training as required by the institution. The transcriber accessed the audio files via the restricted access folder on the secure drive at the University of Sheffield. Audio recordings of interviews were destroyed once the interviews had been transcribed and analysed. All

anonymised data (transcripts and analysis files, demographic questionnaires, capacity assessments) will be kept for five years after completion of this PhD. Signed consent and permission to contact forms will also be kept for five years. Data is stored on a password protected computer on the restricted access folder held on a secure drive at the University of Sheffield and hard copies kept in a locked filing cabinet.

In this thesis and when disseminating findings through written reports, journal articles or presentations individuals will not be identified. Any direct quotes will be anonymised. All participants were reassured of the steps taken to maintain their anonymity and confidentiality at the beginning and end of interviews.

3.9 Data Analysis

All interviews were transcribed verbatim and checked for accuracy. I transcribed the focus group and pilot interview myself, all others were professionally transcribed. NVivo 12 qualitative research software was used to store and organise the anonymised data.

3.9.1 Thematic analysis

Thematic analysis (159–161) was used to identify the key themes presented in Chapters 4 and 5. I felt this method facilitated a flexible approach. It is used by a range of disciplines, including those with a health focus (159). It enables researchers to use both a deductive and inductive approach. It offered a systematic way and clear guidance about how to code the data and identify themes (160). This approach offers the opportunity and structure to use both 'a priori' codes as well codes to be identified from within the data. However, when coding transcripts I mostly used an inductive approach i.e. creating codes from within the transcripts. This was because initially I had thought a deductive approach (i.e. using a priori codes) based on topic guide questions would be useful alongside an inductive approach. Yet, when I began coding I found I was rarely coding content in the transcripts to a priori codes but created new codes iteratively as I read each transcript. There were a few exceptions however, when I did code to a priori codes based on topic guide questions (for example, 'what else might need' 'how to live well with dementia' for the transcripts from people with dementia and family members and 'types of intervention' for staff transcripts). Thematic analysis techniques used to analyse data are not linked to one particular theoretical stance so this suited my epistemological and ontological approaches. I wanted my analysis to inform recommendations and implications for dementia practitioners and services, as well as researchers. I felt this approach to analysis could facilitate findings to be

presented in an accessible way for non-academics, as well as academics (159). Table 3.2 summarises the phases of thematic analysis I employed.

Table 3.2 Phases of thematic analysis (160)

Phase of thematic analysis		How I applied this for this analysis
Phase 1	Familiarisation	- Each transcript read several times - Notes made about content and ideas for initial codes
Phase 2	Generating initial codes	- List of initial codes produced, applied to each transcript, list edited iteratively until all relevant data coded. This process was 'theory driven' (160) (p.88) as a result of asking particular questions of the data i.e. what did people say that appeared relevant to their uptake or rejection of interventions
Phase 3	Searching for themes	- Codes grouped into candidate themes - Coded extracts tabulated to help identify themes - Mind maps used to help identify candidate themes
Phase 4	Reviewing themes	- Groupings of codes and themes adjusted - Subthemes identified when grouped codes related to an overall theme but also needed specific attention
Phase 5	Defining and naming themes	- Confirmed theme content and named each theme and subtheme
Phase 6	Reporting	- Selected and presented key themes and subthemes in this thesis

To illustrate the process of coding and identification of themes please see Appendix 3.23 (Appendices 3.23.1-3.23.10). This appendix presents two samples of an anonymised transcript (one with handwritten notes and ideas for initial codes, the other, a sample of transcript coded in NVIVO). It also presents the list of codes used within NVIVO, examples of initial handwritten notes and mind maps, then tables with the candidate themes and codes in each theme, the reviewed themes and final key themes identified.

To enhance the reliability and validity (95) and trustworthiness (162) of my findings I also used the constant comparative method (95) within each transcript, each data set and then across all data sets. For example, when identifying themes I examined each transcript to ascertain if and how it contributed to that theme. I also used tables and counts of particular phenomenon, such as types of intervention discussed, to represent aspects of the data obtained (95). I examined potential negative cases that were exceptions or did not fit easily within the themes I had identified (95,162,163). One supervisor coded a proportion of transcripts (n=5) to enable discussion of codes and themes and to enhance reliability. When reporting themes I have provided examples of when only one interview account was dissimilar to others. A triangulation exercise (158) facilitated comparison across interviews completed with people with dementia and family members and interviews completed with staff.

As Lincoln and Guba (162) contend, transferability and applicability are important considerations in qualitative research and depend on the degree of similarity between the sending and receiving contexts. I have reported how this research was carried out, to demonstrate an 'audit' trail of the research process and make clear how and in what contexts the data was obtained, so that my findings are credible and dependable (162). My aim is to enable others to be able to judge whether my findings are relevant to the settings and contexts they work in. I have also used thematic analysis and triangulation to provide a rich description of the data.

Analysis of joint interviews

Analysis of the person with dementia's contribution to a joint interview began immediately after each interview. I recorded reflections about how I felt each person had expressed themselves within the interview, the prompts I used and how I had managed the dynamics and balance of people talking. These were transcribed. I considered these questions again when reading and coding each transcript. I noted further thoughts about how each participant had expressed themselves. I noted whether I felt the person with dementia had been able to express their own perspective and views, or whether I felt that the family member account dominated and why this may have occurred. I coded these reflections to enable to me to judge whether I felt each participant with dementia had been able to express themselves within the interview.

3.9.2 Triangulation

Triangulation can be defined as the combination of multiple methods to study the same phenomenon. When used in qualitative research, triangulation is based on the epistemological position that various types of knowledge can be used to obtain a thorough and in-depth understanding (164). So I used triangulation during the thematic analysis to aid a multidimensional understanding of the data (158). Such exploration aims to increase the likelihood that findings and interpretations are found credible and dependable (162). Denzin's (165) work identified four types of triangulation which are summarised in Table 3.3 below and presented alongside the types of triangulation and data analysis carried out for this study.

Table 3.3 Four types of triangulation and how they were applied in this research

Type of triangulation	Definition	Applied in this study?	How applied in this research
Methodological triangulation	Involves the use of more than one research method or data collection technique	Yes	Different types of data collection techniques i.e. solo or joint face-to face interviews with people with dementia and family members; focus group, individual or paired face-to-face interviews and telephone interviews with staff.
Data triangulation	Involves the use of multiple data sources (e.g. different types of report or respondent groups)	Yes	Different types of respondent groups i.e. people with dementia, family members, different grades and professional disciplines of NHS staff, Alzheimer's Society staff.
Theoretical triangulation	Involves using alternative theoretical lenses to examine research findings (e.g. stages of behaviour change vs. health belief mode)	No	-
Investigator triangulation	Involves two or more researchers in the analysis	Yes	I coded all transcripts. One of my supervisors read and coded five transcripts. We discussed these codes during the early stages of analysis whilst I was still coding other transcripts. Both supervisors contributed to theme development by commenting on drafts and discussing themes.

Process of triangulation undertaken in this research

First I coded all the transcripts from the solo interviews completed with people with dementia. Second, I coded all the transcripts from joint interviews completed with people with dementia and family members. Third, I coded the focus group transcript. Then I coded all the other transcripts from staff interviews.

Data from people with dementia and family members

After coding the solo and joint interview transcripts I found many of the codes generated were similar. Although there were also some different codes generated from the joint interviews. For example, some codes related to interactions between people with dementia and family members, and viewpoints being expressed. But, when it came to identifying patterns across the interviews conducted with people with dementia alone and then identifying patterns across the joint interviews to inform preliminary themes, patterns cut across them both. I decided to combine these two types of data into one data set for further thematic analysis and triangulation.

Data from staff participants

As I developed codes iteratively from the staff transcripts, I found the codes were similar despite having used different data collection techniques, with different types of staff. Of course, each interview gave a different perspective and different detail but when starting to identify themes from codes, these were similar across the staff transcripts. So I decided to combine the different types of staff interview into one data set for further analysis and triangulation. By combining the staff focus group data with the individual staff interview data I aimed to enhance data richness (164). Lambert and Loiselle (164) identify three main reasons for combining focus group and individual interview data:

i)   pragmatic reasons

ii)   the need to compare and contrast participant perspectives: parallel use

iii)   striving toward data completeness and/or confirmation: integrated use

I combined focus group and individual data for staff for all of the above reasons. Certainly, one rationale for collecting data through individual interviews and a focus group was practical. I offered a choice of interview method to try to minimise demands on staff time and increase the likelihood of gaining access to staff via managers acting as gatekeepers. However, combining these methods in parallel also enabled me to compare and contrast participants' perspectives, a benefit of combining focus group and individual interview data suggested by Lambert and Loiselle (164).

When coding and organising chunks of text into themes and reporting I ensured the source of data (i.e. type of interview) and type of participant (person with dementia, family member, member of staff and role) was always traceable and reported.

For the purposes of triangulation I used two different sets of combined qualitative data, as summarised in Table 3.4.

Table 3.4 Final two data sets used for triangulation exercise

Final data set	Types of interview transcript combined into one data set
Data set 1: People with dementia and family members	Solo interviews with people with dementia Joint interviews with people with dementia and family members
Data set 2: Staff	Memory Services 1 staff focus group Alzheimer's Society staff joint interview Other individual face-to- face and telephone staff interviews

Examination and comparison of the codes and key themes between the two different data sets (i.e. interviews with people with dementia and family members and the staff interviews and focus group) found initial coding and key themes was different. This reflected the different types of participant and their roles in relation to psychosocial interventions and dementia services i.e. receiving or providing services. However, there were also some similarities. Therefore, I completed further data triangulation for the two different data sets. This data triangulation across the two data sets aimed to:

i) identify similarities and differences in the key themes across the two data sets to identify if overarching themes could be identified;

ii) inform recommendations and implications.

iii) inform a model of readiness to engage (later re-defined as a summary framework , see Chapter 7 section 7.4)

The process I used for this last stage of triangulation was based on Farmer et al (158) with the aim of enhancing the credibility and dependability of my findings (see Appendix 3.24 for details).

3.10 Participant validation

Participant validation was not completed, although I had initially planned this and obtained ethical approval to send a letter and short questionnaire with a summary of key findings to each participant. However on reflection, I decided not to do this because of the challenges of returning to the participants with dementia 12 to 18 months after interview although they had consented to being contacted again in future. My view, based on my experience with participants during interview, was that many may not recall the interview. Also it was possible that their health, well-being or cognitive abilities may have declined. With adequate funding and time, alternative approaches could have been developed. For example, Birt et al (166) designed a 'synthesised member checking' process. This was designed to address the co-constructed nature of knowledge by providing participants with the opportunity to engage with and add to interview and interpreted data, several months after interview. However, I remained concerned about the potential burden on the participants in my research and their abilities to recall the interview. Also, as I wanted to ensure that perspectives of people with dementia themselves were represented I did not want to pursue participant validation with family members or staff only. As Birt et al (166) recognise, there is a juxtaposition of participant validation with the interpretative stance of qualitative research. Given my theoretical stance I was concerned about how a validation process would generate new data and require new analysis. Given these issues I felt that not completing participant validation was acceptable for this PhD research study.

3.11 Patient and Public Involvement

After proposing this PhD topic to the Chief Investigator of the Valuing Active Life in Dementia (VALID) programme (see Chapter 1 Section 1.2) I presented it at a VALID programme management group meeting. This meeting included experts in the field and two lay representatives who were co-applicants on the programme. Both were former carers of their spouses with dementia. The feedback from this meeting was that this was a worthwhile topic to explore.

I presented the study and participant materials to the 'South Yorkshire Dementia Research Advisory group' in June 2017. The members of this group were people with dementia, family carers and staff working with them. I edited these materials in response to feedback obtained from this group. I returned to this group in December 2019 to present my findings and seek feedback on the lay summary (Appendix 3.25) sent to participants with dementia and family members, which I edited in response to their comments.

3.12 Dissemination and publication

I have sent the lay summary to all participants with dementia and family members who requested this (Appendix 3.25). I have also emailed an executive summary to all staff who requested this and all the services that helped me recruit participants and their research and development departments (Appendix 3.26).

I have presented initial findings to the Royal College of Occupational Therapists (RCOT) Specialist Section Older People Dementia Clinical Forum Study Day (March 2019), the Alzheimer's Society Conference (May 2019), Dementia Futures Conference (University of Sheffield, July 2019) and to Sheffield City Council Link Workers (September 2019). I also presented a poster at the Royal College of Occupational Therapists Conference (June 2019). This and an update was published in the RCOT Specialist Section Older People Dementia Clinical Forum newsletter. A summary of key findings has also been published on the RCOT website.

I will submit a publication to the British Journal of Occupational Therapy, focusing on implications for occupational therapists, as an agreed requirement of funding received from the UK Occupational Therapy Research Foundation.

CHAPTER SUMMARY

This chapter described how this qualitative research was conducted and how my methodological stance influenced the choices I made when deciding how to carry out this research. To aid transparency about the research process, the context and different settings from which I recruited and interviewed participants in are explained. My rationale for carrying out solo and joint interviews, using a convenience sample and the recruitment process has been presented. The data collection processes used with people with dementia during solo and joint interviews and staff, including seeking informed consent are described. I discussed how I sought to support people with dementia participate and express their views during interviews. How I completed thematic analysis of the data and triangulation to enhance depth of analysis and interpretation of findings has been presented. Finally, how I sought public and patient involvement, my publication and dissemination plans and activities were explained.

Chapter 4 now presents the findings from analysis of interviews carried out with people with dementia and family members.

Chapter 4 Findings from interviews with people with dementia and family members

This chapter presents findings from the solo and joint interviews completed with people with dementia alone and those completed with family members. People were asked about the impact of dementia on their lives, their experiences of, and views about being offered and attending psychosocial interventions. First, the outcome of the recruitment and screening process is presented. This is followed by a description of the people interviewed and the different types of interview conducted. Second, I present my findings from the thematic analysis of interviews. Initially the solo interviews were analysed separately from the joint interviews, but as explained in Chapter 3, the codes and themes identified for both were similar. Therefore, findings from the solo and joint interviews are presented together in this chapter, with illustrative quotes from both people with dementia and family members.

4.1 Recruiting participants

4.1.1 Screening and recruitment

A convenience sample of sixteen people with dementia, and 15 family members consented to participate and were interviewed. Initially, 44 people with dementia were identified as potentially meeting the study criteria. Table 4.1 presents the number of people identified at each stage of the recruitment process from each recruitment route.

Table 4.1 Numbers of people with dementia identified at each stage of the recruitment process from each recruitment route

	Stage of recruitment process					
Recruitment route[1]	No contact	Screened	Potentially suitable	Not suitable	Declined	Consented & interviewed
'Join Dementia Research' (JDR)	9	10	19	4	4	2
NHS Memory Service, location 1	2	18	20	5	4	9
Alzheimer's Society, (local branch, location 2)	-	5	5		-	5
Total	11	33	44	9	8	16

[1] no people with dementia were recruited via Memory Service 2; all participants recruited via JDR and the Alzheimer's Society lived in location 2 and were served by Memory Service 2

4.1.2 Initial contact

The family member was the first person who answered the telephone or I spoke to as the named contact for all but one of those who declined or were not suitable to participate. These family members declined on the person's with dementia's behalf or explained circumstances indicating the person with dementia would not meet the study criteria. Therefore in these situations I was unable to speak to the person with dementia themselves. One person with dementia explained by email that she did not consider herself to be in the early stages anymore so we agreed she was not suitable to participate.

For eight people with dementia who participated, the family member was the named contact on the permission to contact form (Appendix 3.2). For six of these, when I spoke to family members by telephone they explained they managed the person with dementia's appointments and speaking by telephone to the person with dementia was not possible given hearing difficulties or the person with dementia did not like speaking by telephone because it was difficult for them. For two, I spoke to the person with dementia after speaking to their family member. For two people with dementia, both a person with dementia and a family member were named as contacts. When I telephoned these people the family member answered so I spoke to them first and the person with dementia afterwards. Six people with dementia were named as the person to contact. As four of these people lived

alone I spoke to the person with dementia and for two I spoke with the person with dementia first and their family member afterwards.

4.1.3 Reasons why people did not participate in this research

Of the 44 people with dementia identified as meeting study criteria, eight declined and nine were not suitable to participate. Various reasons for declining were provided by family members and are presented in Table 4.2.

Table 4.2 Reasons given for declining

Main reason given by family member for declining	Number who declined
Described person with dementia as having difficulty adjusting to diagnosis	2
Described themselves as feeling too busy	1
Described person with dementia as having low mood or motivation	3
Reported person with dementia would not want to participate as does not talk much	1
No reason given	1
Total	8

Various reasons for being unsuitable to participate were also identified. These are summarised in Table 4.3.

Table 4.3 Reasons identified for being unsuitable to participate

Main reason identified	Number identified as unsuitable
Person with dementia moved into care home	2
Diagnosis given more than two years ago	4
Unclear if been diagnosed with dementia	1
Not described as having early dementia	1
Deceased	1
Total	9

4.2 Types of interview completed

Four solo interviews were completed with people with dementia alone and 12 joint interviews were completed with one or more family members alongside a person with dementia.

When discussing arrangements for two interviews with family members by telephone, the family members suggested that the person with dementia would wish to be interviewed alongside themselves and another family member as well. When I met the people with dementia in person, they confirmed they would like the two family members to join them. I

had been prepared to return another time or cancel the interview if the person with dementia did not appear happy with the arrangements, but this was not necessary. For one joint interview when I arrived, the husband explained their daughter was present and his wife (with dementia) and he would like their daughter present during the interview, which I had not been expecting. The daughter had read the study information so I discussed these arrangements with the person with dementia before interview and she agreed she wanted her daughter there.

All those who took part in interviews gave their informed consent. Table 4.4 presents the number of solo and joint interviews conducted.

Table 4.4 Number of solo and joint interviews conducted

Type of interview	Number of interviews
Solo interviews	4
Joint interviews	12
- with 1 family member	9
- with 2 family members	3
Total number of interviews	16

Length and location of interviews
The shortest interview lasted 34 minutes and the longest one hour 26 minutes. The average (mean) interview length was 57 minutes. Fifteen interviews took place in participants' homes, one took place in a family member's home. Each interview was completed in one visit.

4.3 Description of participants

Six men and 10 women with dementia were interviewed. Five male and 10 female family members were also interviewed. The youngest participant with dementia was 66 years old and the oldest 87 years old. The youngest family member was 57 years old and the oldest 80 years old. The length of time from diagnosis to interview ranged from four months to two years. Ten participants reported a diagnosis of Alzheimer's Disease (AD). Four reported a diagnosis of mixed dementia, of these three reported 'mixed type: AD and vascular dementia' and one described this as 'mixed type'. One participant reported a diagnosis of vascular dementia and one a diagnosis of frontal-temporal dementia. For the 12 joint interviews, eight participants with dementia chose to be interviewed alongside their spouse or partner. Two chose to be interviewed alongside their adult children or children-in-law, one alongside a sister, and one alongside a friend. Six people with dementia lived alone, one of these lived in

sheltered accommodation. A summary of the main characteristics of participants and pseudonyms used in this thesis are presented in Table 4.5

Table 4.5 Main characteristics of participants and pseudonyms

Person with dementia	Family member	Type of relationship	Type of dementia diagnosis	Time since diagnosis[1]	Age of person with dementia	Age of family member	Living situation
JOINT INTERVIEWS							
Tom	Sally	Partners	AD	Approx. 2 years	81	69	Lived together
Edith	Liz and Colin	Daughter-in-law and son	AD	10 months	87	62, 64	Lived alone (sheltered accommodation)
Pam	Dave	Wife and husband	FTD	Approx. 2 years	66	64	Lived together
June	Sarah	Mum and daughter	AD	11 months	78	58	Lived with daughter & grandson (daughter's house)
Steve	Jan	Husband and wife	AD	Within last 12	70	70	Lived together
Dot	Jenny	Friends	Mixed AD and VD	Within last 12 months	84	62	Lived alone
Mavis	Maureen	Sisters	Mixed AD and VD	21 months	87	Missing	Lived with daughter's family (daughter's house)
Larry	Irene	Husband and wife	VD	18 months	77	70	Lived together
George	Linda	Husband and wife	AD	4 months	73	72	Lived together
Jimmy	Aida and John	Husband and wife, son-in-law	AD	14 months	75	77, 57	Lived with wife
Kathryn	Phillip	Wife and husband	AD	13 months	80	80	Lived together
Iris	Len and Pauline	Wife and husband, daughter	Mixed AD and VD	5 months	74	Missing	Lived with husband
SOLO INTERVIEWS							
Keith	-	-	'mixed type'	Approx. 1 year	72	-	Lived alone
Sue	-	-	AD	Within last 12 months	80	-	Lived alone
Beryl	-	-	AD	6 months	81	-	Lived alone
Angela	-	-	AD	Approx.2-3 months	70	-	Lived alone

AD Alzheimer's Disease FTD Frontal temporal dementia VD Vascular Dementia [1]Times since diagnosis were reported by participants; where an approximate time is given, this is because participants were unable to recall an exact date or length of time

4.3.1 Occupations at retirement

Participants' occupations at retirement included civil servant, engineer, lecturer, scientist, nurse, secretary, builder and care worker. Occupations have not been reported individually in order to preserve the anonymity of participants.

4.3.2 Personal interests and co-morbidities

During interviews, people with dementia and family members discussed their personal interests, how they liked to spend time and interventions they had been offered or experienced. Some also talked about their health and how other long term conditions affected their abilities to do activities.

Table 4.6 summarises the personal interests and activities discussed during each interview.

Table 4.6 Personal interests and activities discussed during each interview

JOINT INTERVIEWS	Personal interests and activities discussed during interview
Tom and Sally (partner):	Tom talked about gardening and managing his investments online on his PC. They both talked about visiting a relative with Parkinson's and dementia each week. They both said they do most activities together. They tried to walk most days, going into town by bus at least once a week. Tom missed driving, listening to live jazz and cycling. They both talked about how Tom had recently tried cycling again with his son and really enjoyed it. They had looked into somewhere to listen to live jazz but do not want to go out in the evening or to busy pubs.
Edith, Liz (daughter-in-law) and Colin (son):	Edith talked about how much she had always loved dancing, singing and playing piano. She had been a Women's Institute member, icing cakes, flower arranging, quilting and sewing. She said still paints cards. Edith attended church regularly and went out most days for lunch independently to a local café close to her sheltered accommodation. She was known by the staff there and said this was now the only place she goes alone. Edith explained she ruminates about her neighbours and having to do her laundry in the shared facilities, which often kept her awake at night.
Pam and Dave (husband):	Pam and Dave said they walked the dog every day. They looked after their grandchildren before school and two days a week after school. Dave said he does most of the domestic tasks now. Dave also said they were now seeing less of family.
June and Sarah (daughter):	June spent most days at home with the TV on. June was going on holiday abroad soon after the interview, to stay with her other daughter. The plan was for her to fly there independently, after being taken to and met at the airport.
Steve and Jan	Steve talked about how he has always loved vehicles and

JOINT INTERVIEWS	Personal interests and activities discussed during interview
(wife):	mechanics and reading about these subjects. Steve spent his time tinkering in his shed, going out on his motorbike or reading. Steve and Jan had travelled frequently in their retirement. They talked about socialising, having friends and family over, going to friends' houses or out for meals.
Dot and Jenny (friend):	Dot said when she's in the house she needs someone to talk to. Her and Jenny had been working on creating a garden space and liked going out for lunch or coffee, to town, or to buy plants. Dot cooked and cleaned for herself, but talked about often dropping food/spilling things. Dot talked about feeling she was not perhaps able to look after herself totally anymore and was thinking of asking social services for help.
Mavis and Maureen (sister):	Mavis talked about she used to be in an amateur operatic society and local art classes (until about a year ago) and used to enjoy painting at home. Mavis said she does not now go out independently and that her daughters or other family take her if she goes out.
Larry and Irene (wife):	Larry's main interest was now is the horses, he used the internet for this and went into the village independently on his mobility scooter to the betting shop. Irene said Larry cannot remember what he ate yesterday or use the PC for anything else, but can manage his horses. Irene has been caring for Larry full time since his stroke (13 years ago). Irene said Larry used to do the garden and help around the house but thinks since the dementia, his age and long term effects of the stroke have led to him being able to do less.
George and Linda (wife):	George spends his time playing golf, reading, playing the piano a bit and gardening. He also attended a Sporting Memories group at the local library and had been going to that for about the past year (prior to the dementia diagnosis). George was still driving, sometimes did the shopping, went to the gym regularly and took long walks. He followed his local football team and went to watch them if their son is visiting.
Jimmy Aida and John (wife and son-in-law):	Jimmy and Aida walk in into the village every day, taking the bus back if they had a lot to carry. John and their daughter often take Jimmy and Aida out to visit familiar places, as they need to know where the toilets are. Jimmy likes to garden, he makes the bed and makes porridge in the morning. His wife lays his clothes out for him. John says Jimmy needs this support as otherwise he would not remember to change his clothes. Aida described how Jimmy can be disorientated within the home, particularly in the mornings. Jimmy misses driving a lot.
Kathryn and Phillip (husband):	Kathryn and Phillip attended church regularly, as they have for many years and were involved in their local church's welcoming committee. They had spent their retirement holidaying and cruising and liked gardening. They said they do most activities together although Kathryn attends a monthly women's guild meeting alone.
Iris, Len and Pauline (husband and daughter):	Iris relied on Len for help with her personal and domestic care. Len said they try to go out most days, he drives them to a garden centre or shopping centre for coffee or cake. Len plays competitive bowls and takes Iris with him when the facilities are accessible. They go to Church regularly.
SOLO INTERVIEWS	

JOINT INTERVIEWS	Personal interests and activities discussed during interview
Keith:	Keith drove himself around and did his own cooking and shopping. He attended several groups run by the Alzheimer's Society each week. When he was not attending groups run by the Alzheimer's Society, Keith said he looks after his house and goes to watch the football regularly.
Sue:	Sue talked a lot about her family who were very important to her. Her son lived locally and visited most days. She had several grandchildren. Sue said she used like embroidery but finds her sight now makes this difficult. She does not go out alone now as she worries about falling. Sue said she has someone help with the garden and her children hoover for her as bending is difficult. She said she was thinking of getting someone in to help clean. Sue talked about being a member of a local pensioner's club which she joined when she retired (before the diagnosis of dementia). She was the treasurer for this group, although she talked how she wanted to give this up as she had been in hospital too many times and worried about taking the money up to the bank and falling. She talked about the activities she does part of this group, for example bingo and dancing. Although she did not dance anymore she said she enjoys watching. She also described trips away with this group and those they had planned. She had had a four day trip away to the seaside planned, staying in a hotel with this group. She sees friends and goes out for meals with her son regularly. On Saturdays her and two friends go for coffee and shopping. Some Saturday evenings she will go out to the local club, driven there and back by friends. When in the house she described doing crocheting, crosswords or watching TV.
Beryl:	Beryl said she often meets friends in town for lunch and they walked around the park most days when the weather was OK. Beryl joined a walking group on retirement, used to do local art classes, volunteer for the Samaritans and a homeless charity. Beryl said she would like to do something interesting, meet new people and possibly volunteer. She had been a member of a local choir for the past 10 years, which she really enjoyed and wanted to keep going with. She also enjoyed listening to classical music.
Angela:	Angela had been a mature student and talked about how much she valued learning. She said she enjoyed walking, driving, watching films and reading books. She said the doctor said she should give up work and her work colleagues also assumed she would stop working. She appeared devastated by the loss of this work role, something she valued greatly and had worked hard to achieve. She also worried about the loss of income and losing her house.

Interventions described by participants

People with dementia and family members described being offered and participating in different types of interventions. All interventions described were group interventions (offered to either the person with dementia alone or them both jointly). None described being offered one-to-one interventions tailored to the individual needs of the person with dementia or for both people.

Some people with dementia were able to describe the kinds of activities and groups they had taken part in, where interventions took place, how long they had attended for and sometimes the staff or service which provided them. Other people with dementia benefitted from verbal prompting from family members or myself to recall this kind of information. Also, some family members were unable to recall what interventions were called or which service provided them. I was able to discuss and suggest possible interventions that people with dementia and family members were trying to describe, if they were uncertain about what to call them or could not recall some details, given my knowledge of what was available in their local area. From the interviews already completed with staff from Memory Service 1, I knew that CST and maintenance CST groups were initially offered to people with early dementia who attended Memory Service 1 for diagnosis and post-diagnostic appointments and that family members were invited to attend and join in the group with them. I knew from interviewing staff from Memory Service 2 that most people with early dementia attending there were initially offered an education and information group and a CST group after that, to which family members were not invited to attend.

A few people with dementia and family members talked about being offered or attending dementia information seminars or sessions at Memory Service 2. One person with dementia and family member talked about attending an exercise group at Memory Service 1.

Several people with dementia and family members described attending memory cafes, in both locations. Several people with dementia and family members in both locations talked about attending a singing or choir session for people with dementia and carers, and sometimes also dancing there, with other people with dementia and staff. These interventions were likely run by the Alzheimer's Society or jointly between the society and NHS services. These choir sessions were referred to by some as 'Singing for the Brain'. One person with dementia talked about going to a group at a university to make a book about her life and times gone. I knew that a local university ran a Life Story group in location 1. Some people with dementia also described going to the Alzheimer's Society in location 2, where they met and talked in a small group with other people with dementia and a member of society staff.

Many of the people with dementia and family members also described attending community based activities not aimed specifically at people with dementia, for example, groups or particular services at their local church, a pensioners club, a craft cafe, a sewing group at the local library, a local community choir, and 'sporting memories' group at the local library.

Three family members also described interventions offered directly to themselves or others as carers. For example, one (John) talked about Jimmy's wife having attended some cognitive behavioural therapy sessions with a psychologist at memory services. Another (Len) described having attended a carer's group run by the Alzheimer's Society and having had a visit from a carer's support service. Another (Irene) reported being offered a carer needs assessment from social services.

Also, during interviews some people with dementia and family member talked about other long term health conditions and their impact. Thirteen of the 16 participants with dementia reported living with sensory or physical impairments or other long term health conditions. Six family members also reported long term health conditions. Table 4.7 summarises the co-morbidities reported by people with dementia and family members.

Table 4.7 Co-morbidities reported by people with dementia and family members

JOINT INTERVIEWS	
Person with dementia	**Family member**
Tom: visual impairment due to glaucoma, systemic sclerosis	**Sally:** under active thyroid
Edith: none reported	**Liz** (daughter-in-law): none reported **Colin** (son): debilitating migraines
Pam: epilepsy	**Dave:** back pain
June: registered blind due to macular degeneration, limited mobility due to knee and ankle problems, under active thyroid	**Sarah:** peripheral vascular disease, heart condition (no impact currently)
Steve: Type 2 diabetes	**Jan:** none reported
Dot: visual impairment due to macular degeneration, chronic ischemia, renal failure	**Jenny:** none reported
Mavis: hearing impairment, sleeping a lot	**Maureen:** none reported
Larry: severe stroke 13 years ago and several 'mini strokes', kidney tumour, uses mobility scooter outside, able to walk inside with stick short distances	**Irene:** none reported
George: none reported	**Linda:** reported low mood
Jimmy: hearing impairment, visual impairment (severe glaucoma)	**Aida (wife):** medication for anxiety, hearing and visual impairment John (son-in law): chronic back pain
Kathryn: hearing impairment	**Phillip:** none reported
Iris: severe stroke 12 years ago, right sided paresis, uses wheelchair to mobilise	**Len (husband):** none reported **Pauline (daughter):** none reported
SOLO INTERVIEWS	
Keith: hearing impairment, series of falls, tremors in upper limbs, urinary continence issues	-
Sue: falls a lot, past 'bleed on brain'	-
Beryl: past transient ischemic attack, allergies/sinus problems	-
Angela: none reported	-

Pen portraits are appended to provide more detailed information about individual participants, the interventions they discussed, history of diagnosis, co-morbidities and their social support networks (Appendix 4.1).

How interviews were conducted

For joint interviews, before beginning I explained I would like to ask the person with dementia questions first and then the family member(s). I tried to sit closer to the person with dementia than family member, if possible. When talking to the person with dementia I tried to maintain eye contact and turn my body towards them, if possible. However, as these

interviews progressed I did not always keep rigidly to this format as the conversation developed fluidly between the person with dementia, the family member(s) and myself. Solo interviews were conducted as planned.

4.4 Findings from thematic analysis

Overall, analysis of my reflective notes suggested that most participants with dementia during the 12 joint interviews were able to communicate and express their views, but this was variable. During five of these joint interviews, I found that the people with dementia (Edith, June, Steve, Dot and George) were able to express themselves within the interview, that I elicited their perspective, as well as that of their family member, and that the person with dementia talked throughout the interview. For four of the joint interviews, the family members talked a lot more than the person with dementia (Tom, Mavis, Jimmy, Kathryn). However, I also found the people with dementia were expressing themselves within the interview. Although sometimes this involved short sentences, facial expressions also aided my understanding of their views in response to my questions and the discussion with their family member(s). I gained understanding about these people with dementia's views of interventions, their interests and possible needs, despite their family members talking a lot more than them and dominating the interview. Also, there were occasions within these joint interviews where these participants expressed different views to their family member. There were three joint interviews in particular during which I struggled to elicit the views of the person with dementia (Iris, Larry and Pam) clearly and the family member account dominated. I had found it difficult to manage these family members' desire to talk. I also found these three people with dementia appeared more moderately affected by memory loss and impaired communication skills, compared to the other participants with dementia that I interviewed. However, even within these three interviews, I did gain some understanding of the person with dementia's own view, albeit perhaps in a more limited way than the other interviews.

For some participants with dementia the person with dementia gave short answers or often had to think for some time before responding or needed questions repeating or rewording (for example, Iris, Mavis, Tom, Larry and Pam). With these people I used written prompts to clarify a question if the person could see to read or photographs to stimulate discussion. I also found that other people with dementia talked a lot or gave long answers or could at times appear tangential (for example, Edith, June, Keith, Sue, Dot, Mavis, Beryl, Angela). For these people I sometimes used written or verbal prompts to re-focus the discussion or sometimes they asked me to repeat the question realising they had gone off topic or had

forgotten what they were talking about. For two people with dementia (Steve and George, both of whom had been diagnosed just a few months before interview) the way they talked and replied to my questions it was hard for me to discern verbal communication impairments, apart from some mild difficulties recalling recent events or dates.

During the interviews, participants were asked about their experience of living with dementia and what type of interventions they had been offered, accepted or declined. Most talked about their experiences of being diagnosed with dementia, how they coped with the challenges and their lives more generally, including how they spent their time and what they enjoyed doing, both now and in the past.

Five key themes from all the interviews with people with dementia and family members were identified. These were:

- Theme 1: Adjusting to life after a diagnosis
- Theme 2: Intervention appeal and perceptions of benefit
- Theme 3: The service context
- Theme 4: Relationships
- Theme 5: Unmet needs and suggestions for services

These five themes are now presented with illustrative quotes.

4.5 Theme 1: Adjusting to life after a diagnosis

This theme is about the process of adjusting and developing awareness of impairments or challenges related to dementia, which seemed to contribute to intervention uptake. There was variability amongst participants' with dementia responses to diagnosis and the perceived impact of dementia on their lives. Some explicitly acknowledged the diagnosis and impact of dementia on their lives whilst others did not. How people with dementia and family members described responding to the diagnosis of dementia varied. For some participants with dementia, the diagnosis had been a shock, as they had not noticed changes such as memory or behaviour changes. Some accounts from people with dementia indicated that seeking and receiving the diagnosis had been anxiety provoking and traumatic, and they felt frightened and anxious for the future. Other people with dementia appeared less so, or did not talk to me about such feelings. The following quote demonstrates the trauma experienced at being diagnosed and trying to adjust to this news:

> Angela (with dementia): *".... at first I wanted to kill myself. Because I couldn't see a future* [starts to cry] *....suddenly I've got this label* [struggling to talk, crying] *and I just, I*

just thought I'd rather be dead…it's going to go into decline from now on. And you won't even know who people are after a while, no thank you, I don't want it…"

Angela also talked about attending a cognitive stimulation therapy (CST) group. This suggested that despite the difficulty she was having adjusting to this diagnosis, and perhaps because of it, she was open to offers of intervention. She described the CST group as offering her a comfortable space where she did not feel judged. For some participants with dementia, stigma and fear also seemed to play a part in how they were adjusting. George (with dementia) and Linda (his wife) explained how they had told only one relative but no other family or friends, including their children, about his diagnosis yet. During another interview Maureen (Mavis's sister) told me the family did not use the word 'dementia' in front of Mavis (with dementia). This may have been to avoid upset or distress and also suggests the word had a stigma attached to it. However, this had not prohibited Mavis from engaging with the CST group she attended, or being keen to attend other interventions that might be offered.

4.5.1 Subtheme: Self-Awareness and differing accounts of dementia

This subtheme is about how aware the person with dementia appeared to be of their diagnosis, the impact of dementia on their lives and awareness of their own needs. It is also about how some people with dementia expressed different perspectives or understandings about living with dementia compared to those given by family members.

Most people with dementia spoke about changes in themselves that they had noticed and some talked explicitly about changes in their memory or behaviour. Some of these participants did not use the term dementia and in some instances their accounts suggested they did not feel dementia to be the primary cause of their difficulties, either because they did not feel any different or due to co-morbidities.

For some people with dementia, acknowledgment of the diagnosis or of changes in their abilities and needs seemed to have encouraged their acceptance of interventions. The ways in which participants with dementia responded to diagnosis, their self-awareness and responses to interventions, varied. Some acknowledged difficulties they were experiencing, such as memory problems and were keen to attend interventions (for example, Edith, Keith, Dot, Jimmy). Some acknowledged difficulties which they related to dementia but also described being uncertain about or not being keen to attend interventions. However, these people with dementia also described having attended interventions, with encouragement from family members, or being willing to try or were planning to do so (for example Tom, June, Steve). Others discussed how they did not feel really any different or did not openly

acknowledge or use the term dementia during interview but had still engaged in some interventions offered (for example, Angela, George, Beryl and Kathryn).

Edith, for example acknowledged her memory was not what it had been and she was keen to keep busy and enjoyed socialising. She attended a memory cafe, a CST group and a craft group. Her family's support with organisation and travel enabled her to engage with interventions but Edith's uptake was also due in part to her acknowledgement of her changing abilities. The following quote illustrates how Edith acknowledged the symptoms of dementia she experienced:

> Edith (with dementia): *"There are times when I get mixed up…Well I'm sometimes scared...Err. And I can't do the things I used to do. Although I do try, I finished a patchwork blanket... I have been to the doctor. And I think he has said there is something wrong with my memory...But everything comes to an end."*

Steve provided another example of how being able to acknowledge the diagnosis or the impact of dementia encouraged uptake of what was offered through services. Steve talked about how frustrated he could become when he could not remember or felt muddled, explaining:

> Steve (with dementia): "…n*ormally I'm fairly placid, calm but if I blow I tend to blow big style… I'm patient for quite a long time and then like I just go bang. Which I didn't used to..."*

Steve said he was doubtful about attending the CST group he had been offered, but had agreed to go, as he acknowledged things were changing for him and was willing to try what had been offered.

For some people with dementia being able to talk about the impact of dementia on their lives appeared difficult (for example, Pam, Len, Jimmy, Sue, Mavis and Iris). Whilst some of these people with dementia seemed to demonstrate limited self-awareness about the impact of dementia during the interview, they openly acknowledged the impact of co-morbidities such as limited mobility, hearing or sight loss. Perhaps this was because they experienced these aspects of their lives as being more impactful than anything else at that time. Some people with dementia talked of anxiety about falling, not being able to see well and being unable to go out independently. This awareness of their needs and challenges, whether or not they articulated an awareness about the impact of dementia seemed to encourage these people with dementia accept interventions. The following example from Sue, who discussed how much she enjoyed attending a CST group, illustrates how she accounted for the challenges she faced:

Sue (with dementia): *"No. I don't want to acknowledge it* [dementia]...*I like to kid myself, that I'm not too bad...I don't forget as far as money and things are concerned…I still do my banking … some days … I think it's this bleed…So I just rest…I don't go out on my own now because I'm frightened…I'm not thinking about it.. I go to a group as long as it's not too bad because at the moment I've still got my faculties, I can remember everything. I can even remember from being three years old…when the blitz was on. I'm not as quick at adding up as I was, but I can still do it"*

Differing accounts of dementia

There were occasions when the accounts given by people with dementia and family members differed. In some instances people with dementia talked about how their view differed to those held by other members of their family, or staff. For example, Angela explained:

Angela (with dementia): *"Well I was diagnosed with having Alzheimer's. I still don't believe it. There's a part of me that says they've got it wrong…but I still read difficult books, I still watch difficult plays, I still lead my life in the same way as I've always done, it doesn't feel impaired to me. But they say to me but you wouldn't know that would you (laughs)…My daughter has that's why I went to the doctors in the first place...But I live alone so I haven't got someone telling me on a regular basis…"*

Yet, such different understandings and perspectives of dementia had not prevented some people with dementia accepting some interventions. In part this appeared to be because family members and staff seemed to be steering a path between their own and the person with dementia's different ways of acknowledging the diagnosis or impacts of dementia, to facilitate the person with dementia's engagement with interventions.

4.6 Theme 2: Appeal of interventions and perception of benefit

This theme is about the interventions participants talked about being offered, participating in or declining. It is also about whether these interventions appealed to them and whether or not potential benefits were perceived.

Responses to interventions

Some people with dementia described themselves as being keen to try interventions they had been offered or in the future. Others were reticent about whether what had been or could be offered appealed, or had been offered at the right time for them. Reticence was illustrated by Kathryn (with dementia), who when discussing a group she had been invited to, said::

Kathryn (with dementia): *"I'm not really, to be honest I'm not really sure because there's so much, I seem to get myself into all sorts of things... the paper for a start we do all the puzzles between us don't we...So we are always doing something you know aren't we".*

Whereas Edith, when I asked her if she would like to attend more interventions similar to ones she had already attended at memory services and the Alzheimer's Society, illustrates a readiness to try interventions offered:

> Edith (with dementia): *"Yeah I would...yes, I enjoy it...I don't mind, try anything. I don't think you should criticise before you've tried it. They've always been okay. I've enjoyed it, and I love dancing".*

Of the 16 people with dementia, 14 described participating in at least one intervention. Two people with dementia and their family members explained that they had not participated in any interventions, at the time of interview. One (Steve) said he planned to attend a CST group he had been invited to in the near future. For the other (June) her daughter talked about planning to organise a lunch club for June to attend in the near future and June said, during interview, she was willing to consider this.

Social interaction and peer support

Interventions offering the opportunity to socialise seemed to appeal to many of the people with dementia, and their family members. Some people with dementia talked about how they socialised less with the impact of dementia on their lives. These people with dementia seemed aware of their need to mix with people outside their own home environment and this was something they seemed to feel group interventions such as CST or memory cafes offered them. Some family members also talked about increasing isolation and the support they gained from attending memory cafes, 'Singing for the Brain' or CST groups they had been invited to attend . Some participants with dementia and family members liked the idea of meeting other people in similar situations. For example, when I asked Pam (with dementia) if she enjoyed attending a CST group we had been discussing, she replied:

> Pam (with dementia): *"Makes a change, yeah, nice to meet people, same as me…"*

Dave (Pam's husband) also talked about seeing friends and family less. He described this being the case since he worried about Pam's changed behaviour, a symptom often associated with a diagnosis of frontal temporal dementia. The following quote illustrates the appeal of and benefit felt by Dave, in terms of the support he gained, when discussing his and Pam's attendance at CST groups and memory cafes:

> Dave (husband): *"Yeah, aye, instead of sitting looking at the four walls all the time…for instance when we went [to] that one at [memory services] for that 14 week course…A lot of interesting people…share their experiences and that..."*

Four of the six people with dementia who lived alone (Keith, Beryl, Angela and Dot) talked about feeling lonely or low in mood at times. Liz (the daughter in law of Edith, who lived

alone) described how Edith had often used to say she was lonely, before they had established a routine of social activities, which Liz and Edith's son drove her to. Sue who lived alone did not talk about feeling lonely but did talk a lot about the friends and family she said she saw often. It was clear how much she valued this social contact and the activities they did together, particularly as she no longer went out alone as she feared having blackouts and falling. Despite describing a network of friends and family, Sue also said how much she had enjoyed meeting new people at the CST group her son accompanied her to. Interventions that offered these people chance to regularly meet and talk with other people and get out of their homes appealed to them. For example, Angela described that friends had 'fallen away' since telling them of her diagnosis and that her family were visiting less; Keith and Dot were both grieving the death of their spouses. Both talked about accepting all the interventions offered to them. Remaining connected to other people was important.

Memory cafes in particular were discussed by both people with dementia and family members who attended them regularly as creating a sociable, informal atmosphere and an opportunity to talk to others who may understand the challenges faced by those affected by dementia. Also some people with dementia and family members described the choir like atmosphere of 'Singing for the Brain' and how at some of sessions, dancing, particularly appealed to them as they had always enjoyed these activities prior to dementia, or found them enjoyable now.

Cognitive or mental stimulation

Interventions being perceived as offering opportunities to engage in stimulating activities was another influence on uptake. Most participants with dementia seemed to understand that mentally stimulating activities were likely to have benefits for themselves and others with dementia, as illustrated by the following quotes:

> Dot (with dementia): *"Yeah I think, I think it's important that you keep what grey cells you've got working if you can, I mean you know, there's not going to be a cure for donkey's years for Alzheimer's is there? There isn't you know unless you can get something so small that you can, swap, swap a vessel or…."*
>
> Keith (with dementia): *"Well if you look at this one* [a memory café], *it's not just a coffee morning…I go every Monday...they've got facilities like what the others, the cafes, don't have. They have billiards, they have games, I play chess, everything to stimulate your mind".*

Beryl was the only person who talked about attending a Life Story group. She had tried attending a memory café, which she had not enjoyed, saying she had not known what to say to people when there. In contrast, the Life Story group appealed to her. She described

talking to and sharing happy memories with the staff there and being able to reminisce, as she explains:

> Beryl (with dementia): *"…they were wanting me to go back to when I was a child at school, I took, some of the things I told them, they laughed and laughed we all did... because we were really blessed really where we lived I mean it was much more countrified …."*

Different accounts of intervention experiences within joint interviews

Within a few joint interviews the person with dementia gave a different, less positive account of participating in an intervention, or were neutral about it, compared to their family member. For example, Tom was unsure whether he had enjoyed mixing with the people he had met at memory services and participating in a CST group. In contrast, his partner Sally expressed the view that when attending Tom had responded positively, as illustrated by the following quote:

> Sally (partner): "... *you used to come out of them* [CST group sessions] *in great form. But you said something afterwards that you didn't particularly want them, like them or anything like that. But you seemed to be in very good form I have to say after you came out of them."*

However, analysis of the interview data from the majority of joint interviews found that the person with dementia and family members expressed similar perspectives about interventions experienced. For example, Dave (Pam's husband) considered that the structure of the CST group (which he had attended with Pam) had benefitted Pam and it offered them both a comfortable atmosphere. Pam's said that although she had been a bit uncertain about attending initially she said she had enjoyed going and the people were nice. Although some participants with dementia struggled to recall the interventions or type of activities they had joined, with verbal prompting they were able to recall some aspects of their participation and communicate their views about this. For example, Mavis could not initially recall attending a CST group but when prompted about a quiz she had participated in, said she recalled that and then said:

> Mavis (with dementia): *"….I'm quite happy to go, it makes a change you know and meeting other people as well. See I've always been into something or other, either the operatic or…"*

4.6.1 Subtheme: personal narratives

This subtheme is about people with dementia describing themselves, or family members describing them as being particularly suited to an intervention that had been offered. For some, the interventions accepted seemed to 'fit' an individual with dementia's personal narrative. Most of the people with dementia talked about having had valued roles as

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volunteers, in local government, church, choir or rambling groups. They talked about their working lives and previous hobbies and how they had been the kind of people to join groups or had always liked meeting people. It seemed the interventions offered had appealed to some of these people with dementia partly because they were looking for ways to remain connected to other people, to keep active and engaged in their communities. It seemed that the interventions offered by services were regarded as one way of doing this. Also if the specific activities involved in interventions tapped into people's existing interests or valued types of activities such as keeping fit, volunteering, singing or dancing this appeared to positively influence uptake. For example, Keith had a role as an 'ambassador' for the local Alzheimer's Society. His explanation of this suggested regular attendance at memory cafes offered him opportunities to meet other people as well as supporting others by welcoming them and encouraging them to talk or join in. Another example was Dot who liked having company and to help at the tea service for her church despite her mobility and sight difficulties alongside cognitive difficulties from the dementia. In the following quote Dot explains how she responded when diagnosed with dementia:

> Dot (with dementia): "*Oh well, well I decided then and there, I thought right I'm going to join everything. Which I have...Singing for the Brain, just sang at the cathedral …It were lovely weren't it. Yeah, so did that… I go to the dementia cafe…*"

A further example was Edith, who recalled her dancing and singing days, cake decorating, painting and poetry writing during the interview. The following quote illustrates how her family members were confident that CST, 'Singing for the Brain' and a craft group would be of benefit and appeal to Edith as she would enjoy meeting people and doing the activities:

> Liz (daughter-in-law):"*…we knew Edith would …want to go to anything she could really…she used to be, as a younger person she, you were quite active in things like WI and all that weren't you?... then there's the Singing for the Brain. We knew she'd like that because she used to be in choirs…*"

Several participants also talked about being willing to try something new. This attitude seemed intrinsic to their coping styles, as illustrated by this quote from Steve:

> Steve (with dementia): "*Yeah I'll give anything a try…. Well you can learn from other people's experiences, can't you? So you know you don't know. I mean even a big head like me doesn't know everything.*"

Intervention offers not appearing to 'fit' personal narratives
However it is important to highlight that some other people with dementia talked about some interventions that had been suggested, but, did not appeal to them. Some people with dementia talked of feeling shy or under confident given their reduced memory or being

uncertain about mixing with unfamiliar people. Some also suggested their lives were full enough and they were busy enough. These views had the potential to discourage uptake. The following quote illustrates Tom's limited enthusiasm for the interventions he had been offered:

> Tom (with dementia): *Yeah really I probably wouldn't do it if I had my memory so (Laughter)…Some of the memory, say you go down, but they [are] probably people who I wouldn't talk to anyway (laughter)…. That's the way I feel about it….yeah they've got these memory clinics or you can go to coffee bars and stuff like that. But I've got other things to do (laughter)."*

June and Sarah (June's daughter) were the only participants who discussed declining all intervention offers. There were several reasons for this: the idea of a group where June thought she would be expected to talk about dementia, a previous experience of attending a group for people with visual impairment she had not enjoyed and her former work experience all appeared to influence her rejection of offers such as memory cafés or groups at memory services. The following quote from June illustrates June's her of what had been offered so far:

> June (with dementia): "*...years ago...I've worked… on mental health units… I understand all this... It's all sitting round, all having to talk about what they feel because I think it's personal to yourself and I don't think it should be voiced on the stage…It's as if you've got a bad marriage, you wouldn't like to sit in a group talking about what your husband does and what. I just think it's personal… Everybody don't feel the same if they're losing their sight or losing their memory. I don't know… If there were suddenly a couple in here, going through same thing, I would be willing to sit and discuss it. But I don't want a wider audience.*"

There were also a few examples of family members explaining the person with dementia had been uncertain about trying an intervention (for example, George and Tom) or people with dementia themselves saying this (for example, Pam, Tom, Angela, Beryl, Sue). A few family members had also felt uncertain about whether the person with dementia would enjoy it or benefit from participating (for example Jan, Steve's wife, and Sarah, June's daughter). However, for most of the people with dementia that had attended an intervention, the person with dementia (and family member in joint interviews) described attending as a positive experience. Thus it seemed whilst some people with dementia or family members had perceptions about what may be enjoyed these were not always borne out. This suggests that for some participants, trying an intervention despite reservations resulted in some benefits such as social interaction or engaging in an enjoyable activity even if it was something the person with dementia may not have done previously. Being willing to try an intervention and positive attitudes towards trying new activities seemed an important influence on uptake. One illustration of this was George. Both George himself and his wife Linda had been

surprised that George had joined in with a 'Singing for the Brain' session, singing and dancing, when he had been reticent beforehand and Linda had thought it would not 'fit' George's personality. When we discussed what led to him enjoying the session, George indicated that being with other people collectively singing and dancing had contributed to his enjoyment and engagement by saying:

> George (with dementia): *"Suppose if there was just two or three there I wouldn't be motivated to get up and shuffle around the room would I…"*

4.6.2 Subtheme: Mixing with others with dementia

This subtheme is about how the idea of mixing with others with dementia appeared to discourage uptake for some people with dementia, making them feel anxious or uncomfortable. A few people with dementia (for example, Angela and Beryl), were worried that people in intervention groups may be more severely affected by dementia and they were uncertain about communicating with them or it made them fearful of what the future held. One family member (Linda, George's wife) expressed a similar view, although George did not articulate this himself, he did talk about not wanting to tell other people he had dementia. Although such feelings did not always result in these people with dementia declining interventions, it did discourage some, as illustrated by the following quote:

> Beryl (with dementia): *"… I know there's a walking group within the Alzheimer's but I don't know really about that… how far down the line would they be with their Alzheimer's? I'd want to be able to go and just converse with somebody who's able to, you know."*

The importance of activities not targeted only at people with dementia

Being involved in community based activity or groups not specifically targeted at people with dementia also seemed important to many of those with dementia. Most people with dementia talked about their involvement with community groups, such as church groups, a community choir (not aimed at people with dementia), a pensioners group or day trips. These were activities that these people had taken up in retirement and wanted to try and continue. Such activities were not aimed at people with dementia specifically, were clearly valued and talked about enthusiastically. These people with dementia perhaps valued the 'normality' of continuing to participate in interests and activities. The following exchange between June (with dementia) and her daughter illustrates this dilemma:

> Sarah (daughter): "... *I think what mum wants from support is somewhere where she can go and be who she was and who she wants to be rather than being forced into a mould of you know the illness*
>
> June (with dementia): *Correct Sarah. Our Sarah knows me more than anybody*...

Sarah: *...And sit and do normal things like chat and have lunch... have coffee... just talk about the weather... things that normally people would do when they meet up. Rather than 'oh here's an activity that we've got you to do to try and help your memory'..."*

4.7 Theme 3: the service context

This theme was about the context created by the services that offered interventions. The way post-diagnostic support and interventions offered by memory services or the local Alzheimer's Society differed. This could influence individual experiences. A subtheme about signposting was identified as this appeared a key feature which could facilitate uptake of interventions. Another subtheme identified was about the impact of practical issues, such as locations, travel and venues

Experiences of memory services

Most people with dementia and all family members described the process of the person with dementia receiving assessment at memory services and then being given a diagnosis. Some described being given information about psychosocial interventions at the point of diagnosis or afterwards at an appointment with a memory services nurse. Some family members also described how within these post-diagnostic appointments at memory services, medication was reviewed and information given about other support services. The following quote from Linda (George's wife) illustrates her perspective of their joint experience at memory services:

Linda (wife): *"...at the memory clinic they overwhelm you with information and invite you to all these things like you could be there every day of the week...anyway they tell you about all these workshops and oh I can't even think about what there were. ... I think they throw everything at you, in less than an hour or something, and it's just variable what sticks or what goes in..."*

Experiences of the Alzheimer's Society

Some people with dementia and family members talked about contact they had had with the local Alzheimer's Society and some interventions provided by the society. There were examples given of personal contact with Alzheimer's Society staff such as telephone calls or letters. For example, Dot talked about receiving a letter from a member of Alzheimer's Society staff saying she was sorry to hear she had been ill. The following exchange between George and Linda illustrates how they both had appreciated the approach taken by a member of staff from the Alzheimer's Society, although George did not like the word 'Alzheimer's':

Linda (wife): *"...I just said she's just coming to see if there's anything she can offer us and you know...mentioning Alzheimer's Association and that. But...*

George (with dementia): *It's that word you see*

Linda : *...she didn't push anything, she was very calm and slow and...she only mentioned a few things that she thought might appeal to us, she didn't throw the book at us. And then she said think about it. And she didn't throw loads of leaflets*

George: *Gently gently. Softly softly"*

Methods of invitation to interventions

When I asked people with dementia and family members how they had initially been invited to take part in interventions some could not recall this. During joint interviews, it was usually the family member who responded to questions about how they both or the person with dementia had been invited to participate in an intervention. Personal contact, by telephone or face-to-face seemed to be positive influence on uptake, although some people had attended memory services after receiving just an appointment letter.

When talking about memory services, those who could recall how they had been invited said they had been sent appointment letters or had received a telephone call. For example, I asked Tom and Sally how they had been invited to the education and information group sessions they attended at memory services, and they replied:

Sally (partner): "*No it would have been through the post. I think they were all pretty much through the post*
Tom (with dementia): *I think my son picked up the first one and then they followed on from there"*

Dave (Pam's husband) explained Pam and himself had been invited to a cognitive stimulation therapy (CST) group by letter. The following quote suggests the personal telephone contact Dave had with a member of staff, reassuring them they could still attend despite having missed the first session, as well as Dave's proactive behaviour in contacting them and this service's flexibility helped facilitate their attendance at the CST group:

Dave (husband): "*They sent a letter and I got in touch with them and erm they says like I think we missed the first one because I'd been to the doctors, missed the first one and er she says come to the second one, we did, started from there ...*"

When I asked Sue (with dementia) how she had been invited to attend a cognitive stimulation therapy group, she described a doctor at memory services inviting her. The following quote illustrates how this appeared to encourage Sue to attend, as well as her son's support:

Sue (with dementia): *"...went to see a doctor at the memory clinic...She was nice, she was nice, and then she said would you like to go there* [to a CST group] *and (name/son) said yeah I'll take her, it'll do her good".*

When talking about interventions offered by the Alzheimer's Society staff some people with dementia and family members recalled being contacted in person or by telephone to discuss possible interventions and whether or not they would like to attend. The drop-in nature of Alzheimer's Society memory cafes, where an appointment was not necessary and the location, for some, was convenient, perhaps encouraged some people to attend. For example, when I discussed their attendance at a memory cafe with Kathryn (with dementia) and Phillip (husband) they explained how memory services staff had told them about the memory cafes, this signposting, along with the drop-in nature of the intervention and a convenient location for this couple, appeared to have encouraged their willingness to try it :

Phillip (husband): "*I think it was when we first went to the memory clinic...*
Kathryn (with dementia*): Oh it was wasn't it, yes that's right*
Phillip: *We just went*
Kathryn: *We just went* "

4.7.1 Subtheme: Signposting

Some people with dementia and most family members described being given information about support services, including psychosocial interventions, either by the Alzheimer's Society or NHS staff.

Positive experiences of signposting

Several family members described being given an information pack by NHS memory services. These were described as containing lots of information and leaflets about the Alzheimer's Society, memory cafes, interventions offered by memory services, research studies, carers support services and benefits advice. In some joint interviews it was clear that information packs were kept for future reference by the family member and the person with dementia had little or no recall of this information.

Some family members and one person with dementia described having attended an information session about local services, benefits and support available in their area. This signposting role was mostly perceived as useful by the family members and person with dementia who discussed this. For several people with dementia and family members the information provided had led to the person with dementia trying a new intervention, or the

family gaining legal or benefits advice. Also, some family members talked about memory services staff offering practical help, identifying other health issues or facilitating referrals to social services. This type of signposting and associated interactions seemed to foster a context which then positively influenced uptake of interventions by the person with dementia. The following quotes highlights how these family members found the signposting function provided by memory services useful and considered it of benefit to the person with dementia they supported:

> Liz (Edith's daughter-in-law): *"… if we'd not gone to that CST…I don't know if we'd have got all this other information we'd have had... They referred us to dealing with...attendance allowance which we didn't even know existed...this care company … every other day they come just for a half an hour…had it not been for the memory service we would not have known... And it was from the CST groups...we found out about the memory cafes, and the crafty café…"*
>
> John (Jimmy's son-in-law): "*Again the lasses there, they'll help you fill any form you need filling*"

One person with dementia referred to being referred to physiotherapy, when attending memory services. This was clearly valued and seemed to foster a positive relationship with the memory service, as the following quote illustrates:

> Dot (with dementia): *"...somebody said why are you walking like that? I said I've only got half me things working anyway, she said have you had a stroke... she said would you like some physio and I said yes please…It was... good actually because from then, when one lot stopped another lot started.... And you thought 'yeah I'll get there'".*

Negative experiences of signposting

For two family members, signposting of information about benefits was experienced as misleading or upsetting. The following quote illustrates how for some, receiving benefits advice was a sensitive issue, the difficulty of offering 'blanket' advice or perhaps this family member's concern about the future:

> Linda (George's wife): *"…And the nurse mentioned the attendance allowance and I started crying didn't I? Because I said 'well George can do everything for himself you know, why are you talking about the attendance allowance?'… I applied for it...I think she implied that if you get the diagnosis, you get it. So I phoned the Alzheimer's for help with the form... he didn't get the attendance allowance because he isn't, doesn't need that personal care. So I thought was a red herring that didn't need to be mentioned among all of the other stuff."*

4.7.2 Subtheme: Practicalities – timing, location, travel and venues

Timing

When asked when people with dementia should be offered information about support services and interventions, in joint interviews most family members expressed the view that

offering this as early as possible after diagnosis was advisable, and mostly the person with dementia agreed with this view. In solo interviews, people with dementia also expressed this view. The following exchange between a husband and wife illustrates how a positive experience of a CST group influenced the husband's view that interventions were best offered as soon as possible:

> Dave (husband): *"I would say as soon as possible me.*
>
> Pam (with dementia): *Yeah I would*
>
> Dave*: As soon as you're diagnosed I would think especially for the cognitive stimulation therapy I think that's a big thing that. Seeing how it changed Pam… I don't know if it was just doing it time after time after time. Maybe that's probably why they do it…most of them I would say you could see the difference it had made to them as the course progressed."*

The following quote illustrates a similar view and that offering interventions soon after diagnosis had been valuable to this family member:

> Sally (partner): *"…we…went together for the diagnosis... they handed us a big fat folder of information about various things about Age Concern about er their cafes and this sort of stuff... But after that it* [attending education/information group sessions] *was immediately, fairly immediate after that. And I was delighted because as soon as I found out...I obviously wanted to do something about it. And that felt like doing something about it. So as quick as possible was my, it suited me perfectly."*

Jan (Steve's wife) expressed concern that the CST group offered felt a 'bit early' for Steve, as he was recently diagnosed and Steve agreed. During their interview Steve talked about his life, how he was living life independently, driving, socialising and doing activities pretty much as he had always done. However, both Steve and Jan also acknowledged Steve had memory problems and that Steve could become frustrated. Steve said he would willingly accept support if it could help himself or Jan, as the following quote illustrates:

> Steve (with dementia): *"I'm patient for quite a long time and then like I just go bang. Which I didn't used to… I want anything that'll either help me or Jan"*

Different accounts in joint interviews of preferred timing

Sometimes the person with dementia and a family member expressed different views about whether or not interventions had been offered at the right time for them. The following quote is an example of a couple expressing slightly different views about this:

> George (with dementia): *"I'd recommend it pretty much immediately, you know as soon as possible. Get them, perhaps, there should be more than one a month I don't know*
>
> Linda (wife): *I think it varies, because it can be overwhelming, it's an awful lot of information to process and it's an awful big change in your lives and what I found, like the day I organised for* [staff name from the Alzheimer's Society] *to come here, George*

was very against it and he kept saying today about you coming, 'what's this'. And you know it does create some anxiety in the patient. And luckily, I just said she's just coming to see if there's anything she can offer us and you know I had to be up for it and sell it to George…"

Linda talked about engaging with the Alzheimer's Society interventions and encouraging George to do so. She was perhaps trying to express the need for support to be tailored to individual responses and needs. In response to being asked about if there was a good time for memory services to offer interventions, another person with dementia, June, said she thought this should occur as soon as possible after diagnosis. Yet, June had declined such an offer herself. The following exchange illustrates maybe why June had declined intervention offers and revealed she worries about burdening her daughter:

> June (with dementia): *"Yeah straight away …*
>
> Sarah (daughter): *But you said no straight away*
>
> June: *Yeah but I think now with hindsight, I think you say it because you don't want to be a burden …"*

This illustrates how one individual may have different views at different times, and the challenges this can present.

Locations and travel

Practical issues of travel and the locations where interventions took place in were highlighted by most participants as very important influences upon whether they accepted or rejected interventions.

Most people with dementia who could travel independently by public transport or drive (for example, Steve, Keith, Beryl, George, Angela) or had family members to accompany or drive them (for example, Tom, Edith, Pam, Sue, Larry, Kathryn, Iris), transport was not a barrier. However some, such as Mavis and June, voiced concern about burdening family members with this, possibly because they both had children of working age who supported them. Sarah (June's daughter) and John (Jimmy's son-in-law) talked about how they could not always drive the person with dementia to appointments or intervention sessions given their other responsibilities. For some, such as Jimmy and Mavis, a network of family members were involved in trying to ensure the person with dementia was taken to interventions.

Where participants lived in relation to where interventions were held meant travelling distances could be significant or public transport was not perceived as reliable or accessible. This was particularly the case for those living in small villages. For those living in more urban areas, the length of the journey or parking discouraged uptake. The engagement of participants with dementia in interventions was often entirely dependent on family members

being able to support this. The following quote from Mavis, who could no longer travel independently, illustrates this. When I asked if Mavis if she would be willing to try other interventions she replied:

> Mavis (with dementia): *"Oh fine, as long as they* [referring to her daughters and other relatives] *don't mind. I mean if I went, I couldn't go on me own I don't think because I'd have to catch a bus and then get a taxi whatever…"*

The following exchange between a husband and wife illustrates the impact of this husband's view about driving his wife to a particular venue for a CST group and thus on her ability to engage in that intervention, as she relied on him for transport:

> Phillip (husband): *"Yes they have mentioned them* [CST groups], *but it's a bit of a trial going all that way…. there's no problem getting there but the problem is parking. It's only for Kathryn, not for me so I should, what do I do for two or three hours? I don't think Kathryn was capable, well not capable, but I don't think you'd want to go all that way on your own would you to* [memory services location]?
>
> Kathryn (with dementia): *Go on my own?... Well I couldn't go on my own because I can't drive*
>
> Phillip: *You'd get a bus dear*
>
> *Kathryn: Oh no*
>
> *Phillip: But you can catch bus from this end of town you see …*
>
> Kathryn: *No*
>
> Phillip: *If there was something this end of town we probably would love it"*

Four of the six people with dementia who lived alone were able to travel independently (Keith and Angela drove, Dot and Beryl used buses or taxi's). However, should these people no longer be able to manage the journeys it was unclear how they might access interventions. Dot for example, lived alone, had poor vision, balance and walking difficulties and talked about some financial worries during the interview. She was keen to attend interventions despite these challenges. When I asked how she travelled to the different locations, Dot explained she got buses or taxis, saying:

> Dot (with dementia): *"...I think I can't keep doing this. It's only money when it's gone it's gone."*

Venues

A further influence on uptake were the venues within which interventions were provided and what a hospital or community base may signify to people. For example, George did not want to be seen by colleagues going into the memory service and his wife Linda talked about how they both disliked the waiting room at memory services, having to sit with other people with dementia more severely affected. Jimmy had feared attending memory services initially as

he thought this meant he would be put in a home but once reassured, was happy to return there for CST groups.

Community or local venues seemed to offer an appealing environment to some family members (for example, Linda, Len and Phillip). They talked about visiting other places in town nearby or that the journey was familiar. The following quote illustrates how perhaps a sense of normality was important for this family member and thus may facilitate the person with dementia's engagement in an intervention, given their reliance on the family member to take them:

> Len (husband): *"... there was one* [intervention] *that they particularly mentioned to me... it was going to be a place that was an open garden. Which had a coffee shop in it… Now that sounded as though that would be the sort of place we would enjoy going to...."*

Co-morbidities

Some people with dementia were living with visual, mobility or hearing difficulties alongside the impacts of dementia. These issues impacted on people with dementia's ability to travel and so access intervention venues independently (for example, Sue, June, Mavis, Larry, Iris). For Iris (with dementia) and Len (her husband) wheelchair access was always a consideration as she needed a wheelchair to mobilise. The following quote illustrates, for Larry, the impact of poor balance, limited mobility and dependence on his wife Irene, to travel by car which, they needed to attend the exercise group he attended at memory services:

> Larry (with dementia):.. *it's a big disappointment to me, I have these tumbles, if I turn too sharply I lose my balance and I'm down....*
>
> Irene (wife): ...*he doesn't do much now at all, he used to help around the house, he did the garden and he can't do hardly anything now, and I think it's part of the dementia but I think it's also you know 13 years after a stroke and his age...when he had that fall the other week, paramedic came...he got up...and...she looked at me and said 'does he always walk like that?' I said 'yes', she said 'there's no wonder he falls'....*
>
> Larry: *I have trouble getting out of the car, without hands coming to assist me.*
>
> Irene: *He can't get out of car. Terrible.*
>
> Larry: *Today I wouldn't attempt to get out back of car, I'd be down"*

Some people with dementia also explained how living with co-morbidities impacted on their ability to engage in other activities they enjoyed and wanted to take part in, as illustrated by the following quote:

> Edith (with dementia): *"... I did crochet...but I can't do it now....*
>
> [Becky Field (researcher): *Because of the hands?* [Edith was showing her hands]
>
> Edith: *Yeah*

[Becky Field: ... *a bit...arthritis?*]
Edith: *Yes that's it, that's how it was stayed...I can't play the piano anymore"*

Some family members had their own sensory impairments or health issues to manage but only one (John, Jimmy's son-in law) talked about how this sometimes meant he could not drive Jimmy to appointments, due to having to attend his own health appointments.

4.8 Theme 4: Relationships

This theme is about the relationships that influenced uptake. These were the relationships between people with dementia and family members and, the relationships between staff, people with dementia and families. Two subthemes: 'Encouragement and persuasion', and 'Support to manage fear and anxiety' were also identified.

Relationships with family members: a pivotal role

Family members had a pivotal role in supporting people with dementia to take up intervention offers or alternatively influencing decisions to decline. Family members provided practical and emotional support. In addition to driving people with dementia to interventions, family members described offering reassurance, encouragement and prompting to enable initiation, planning and organisation, which in turn supported people with dementia participate in interventions. For example some family members talked about prompting the person they were supporting to recall dates and times. Some people with dementia also needed assistance to get ready given their difficulties. For example: Irene supported Len with remembering appointments, driving him to an exercise group and attending with him; Edith's daughter-in-law drove her to different groups and had attended some first sessions to check she was happy there but now dropped her off and collected her; Linda had encouraged George to meet a member staff from the Alzheimer's Society and attend 'Singing for the Brain', despite him saying he was not keen to do either; John had taken Jimmy to memory services for assessments and to discuss post-diagnostic support when Jimmy had been very fearful about doing this. Mavis's daughters supported her attendance at CST groups by waking her up and attending with her. The following quote from Mavis's sister illustrates this and the support this family provided to Mavis:

> Maureen (sister): *"...oh it's there there's a craft group...you can do, there's all various things. I mean...I think she would* [referring to Mavis's daughter, with whom Mavis lives] [name of daughter] *is very busy because she looks after her grandchildren, two or three days a week...They have a very busy house. They do remarkably well...*[names one daughter] *drives down from* [place] *every week to take her* [Mavis] *to the memory clinic, except when I'm here and I don't manage to get her out of bed. In short of*

flinging the blankets off her and saying come on...They must be better at getting her up than me, I think..."

Family members appeared to recognise their loved one's needs and provide support, creating a climate in which uptake and engagement with interventions was enabled, particularly if the person with dementia had been uncertain about engaging initially.

4.8.1 Subtheme: Encouragement and persuasion

Some family member accounts suggested they had to encourage or persuade participants with dementia into attending interventions, initially or subsequently. The following quote from Sue highlights the important influence of her son in encouraging her to initially attend a CST group:

> Sue (with dementia): "*No I never thought about it* [attending CST] *because it was* [son] *that pushed me... And I'm really glad I go now because it is nice… He's bossy like his father; 'oh mother come on you don't want to sit in house all day' you know he said,' I'll go with you', and he does and he comes in now. Because a lot of them go with their husbands you know and we have a right laugh, we do have a right laugh…*"

The following quote from Linda illustrates how she tried to encourage George to attend 'Singing for the Brain' when he was not keen, as well and the influence of wider social networks on her approach to this:

> Linda (wife): "*And to go* [to the 'Singing for the Brain' session] *George wasn't keen and gets a bit grumpy, but I said let's try it... I get a bit firm, say let's try it… Because my friend says that... her husband's reluctant to go to anything and moans all the time... then... loves it when he gets there. And your brother's the same they don't go to anything because his wife says no...instead of trying to encourage her to go... in some way you have to be a bit devious I think because when you're well you often don't want to do things..."*

Maureen talked about finding it difficult to help motivate Mavis to get up and attend the CST group, explaining:

> Maureen (sister): "*They* [Mavis's daughters] *do remarkably well…every week to take her to the memory clinic, except when I'm here and I don't manage to get her out of bed. In short of flinging the blankets off her and saying come on….They have a different, they must be better at getting her up than me, I think…Yeah they are a lot younger than me, I'm more like move over!"*

The following quote illustrates how June was willing to be led by her daughter's decisions:

> Sarah (daughter): "*But if you'd have been forced to go to go to one of these groups like you're saying, that you should insist and say that it's necessary, you'd have kicked back. You would have fought it... I'm going to insist on what she does now. Rather*

than leave it to mum to decide, I'm going to put things in place so that she's not got a choice…

June (with dementia): *I don't mind. If it were anybody but her I'd say bugger off I'm not going. But yeah. Sarah doesn't do anything that's spiteful".*

A husband and wife highlighted the challenge of trying to facilitate uptake when it may be unclear if a person with dementia wants to participate. Iris was dependent on her husband Len for mobility. I had asked Iris whether she liked going to the CST group, and the following responses illustrate the challenge of knowing whether attending was valued or not:

Iris: *"Well I go because I've got to*

Len (husband): *There's never been a case of I'm not going there. You know I don't want to go. It's never happened. And normally when we're there it's alright*

[Becky Field (researcher): ….*would you say you enjoy it when you're there?*]
Iris: *I think I probably do. I don't know."*

Participants' wider family or social networks also influenced uptake. Some talked about children, friends and other relatives whose views were important to them and could then influence their responses to intervention offers, as the following quote highlights:

Phillip (husband): *"I think our daughter suggested for her to go* [to a memory cafe]
Kathryn (with dementia): *She did, didn't she ….*
Phillip: *I don't know (laughs) I suppose we accepted that she's you know she's concerned, as much concerned as I am."*

Family members' own needs

Some family members had their own challenges with mental and physical health. This had the potential to affect the support they were able to give to facilitate the person with dementia's engagement with an intervention. Whilst this was not something many family member participants talked about explicitly, a few did. For example, when I spoke to Linda (George's wife) by telephone to arrange the interview she talked to me about low in mood she had been since moving house. Then, during interview they both talked about how George maintained his long-standing routine of waking first, making tea for Linda and going for a walk or to the gym every day. Whereas, Linda explained she had a tendency o to be affected by anxiety and depression and struggled with to be as active as George, as the following exchange illustrates:

Linda (wife): *"...he's up every morning brings me a cup of tea...*
George (with dementia): *Usually follow that up by he's well trained*
Linda: *... he's great at, because I sometimes think, because I'm more prone to anxiety and depression and George never was..."*

John (Jimmy's son-in-law) explained, when seeing me to the door, after a joint interview (between Jimmy, John and Jimmy's wife Aida) about his own health and how Jimmy's wife's mood and wellbeing had deteriorated since the onset of Jimmy's dementia. He talked about how much emotional support Aida required from himself and their daughter, that Aida telephoned them a lot and was anxious, especially if they did not visit each day. John said Aida had received some cognitive behavioural therapy from a psychologist at memory services, but he felt she needed more and ongoing support.

Offering an opt-out

Persuading people with dementia to try an intervention just once initially and offering an 'opt-out' was a strategy described by Linda (George's wife) and Liz (Edith's daughter-in-law) to encourage uptake. These family members encouraged the person with dementia to try an intervention for the first time by reassuring the person that they did not have to continue if they decided an intervention was not for them. June (with dementia) suggested using a similar strategy to encourage uptake. When I asked June what she might advise others with dementia who declined offers of intervention as she herself had done, she replied:

> June (with dementia): *"All you could say to them is why don't you just sit in on one of these groups...They don't have to sign up to it, just come and have a look, and if you think it's for you then join it, and if not then don't come no more."*

Positive relationships and communication with staff

The ability to build a relationship with people with dementia and family members who were struggling to adjust, depressed or uncertain about attending memory services or an intervention appeared helpful in encouraging people feel ready to engage with services and thus interventions. Staff having a down-to-earth approach and communication style seemed important to several family members. The following quote from Dave (Pam's husband), when he was discussing the CST group he and Pam had been to, illustrates how he appreciated the way staff communicated with him, as well as the focus of the group:

> Dave (husband): *"....we missed the first one... and er she says come to the second one, we did, started from there and erm it wasn't just everything about your memory it was things like, they made light of things, rather than being studge, stuffy..."*

Even when conversations were about topics not directly related to intervention uptake, how staff communicated at any time during their contact with people with dementia and family members seemed to help them feel comfortable and supported. In the following quote to John was talking about trying to get advice about Jimmy's medication and how helpful staff

at memory services were:

> John (son-in-law) *"…we'd been to doctors, to consultants, to hospital ...if you need a thesaurus to look at what a word means, it's a bit, you know what I mean… They explain it in a way that makes you feel, you're not patronised in any way...They do it, you've been to group* [the maintenance CST group] *you know what it's like....I sort of get the feeling this is like, they'd do it even if they didn't get paid for it...they all seem to enjoy it…. You said yourself it's like a family isn't it?*
>
> Jimmy (with dementia): *It is yeah."*

The influence of positive personal relationships with staff on uptake, as well as wanting to engage in stimulating activity, is also illustrated by the following response from Beryl. I had asked what had made her willing to try a group offered by the Alzheimer's Society intervention and she replied:

> Beryl (with dementia): *"...Because I like* [staff name] *and the organisers and I think they can probably point me in the right direction of other things to do perhaps and everybody's nice, they are all pleasant people because I've not got much else going on in my life at the moment."*

Less positive experiences of communication and relationships with staff

A few family members were less positive about some interactions they had with memory services staff. These experiences seemed to have the potential to impact on uptake and engagement. The following quote from Len demonstrates this point:

> Len (husband): *"I was starting to get myself a little bit annoyed...when everybody was just, you know the people who take it* [an intervention group]*, were just chattering amongst themselves about what they'd been doing. Now that shouldn't happen....but a lot of the things that they do there are good…"*

Another example of the impact of conversations is provided by George and Linda who experienced the way his diagnosis was given as very uncomfortable. George and Linda had not accepted any offers of psychosocial intervention from their local memory service where George had been diagnosed, but had accepted offers from the Alzheimer's Society. In the following quote they talk the approach of the doctor giving the diagnosis, in contrast to the approach used by the Alzheimer's member of staff:

> Linda (wife): *"I think she [*the member of staff from the Alzheimer's Society*] sat there for about two hours…*
>
> George (with dementia): *In contrast over at the hospital the diagnosis was given by a doctor, and it was very cold."*

The way George's post-diagnostic follow-up appointments at memory services had been managed left them both somewhat unclear as to the purpose and frustrated at seeing

different members of staff. This appeared to create a sense of uncertainty. The following exchange illustrates how experiences of different staff members were recalled:

> Linda (wife):*"… you see different people all the time… you're seen by the nurse now …there was a lovely girl first time...she did you a plan but she didn't write a lot in it…then every time we've seen a different person.. Different people and they all seem to, well I don't know, you wonder why you go….*
>
> George (with dementia): *Well it sort of makes you wonder whether they work independently of each other don't they, instead of as a unit, a team.*
>
> Linda: *But you liked that* [staff name] *didn't you…the last time…*
>
> George: *Well I presented a little bit of information about a drug I'd read about which I think it's on it's third stage… so far the results have been very encouraging… I mentioned that to* [staff name]*…they had a look at it and said oh yeah that looks very good…*
>
> Linda: *… I probably get a bit irritated because I think oh another person I'd want to see the same person who could follow on from some of the things we said the last time...*
>
> George*: Continuity*
>
> Linda: *Yeah some continuity but one thing* [they] *did say… said they really don't know what causes Alzheimer's… I thought well it's nice someone's honest, and obviously you liked talking to [them]…overall I wish they had more continuity. Better record keeping that they could say, are we only going for the drugs? Are we just going to...? You know. …."*

When talking about why she had declined intervention offers, June explained how she thought staff might talk to her, now that she had dementia although her daughter points out June had not been to any interventions for people with dementia. Whilst it was unclear if perhaps June was thinking about staff at group for people with visual impairments she had attended and not enjoyed, or memory services staff encountered during the diagnostic process, or neither, the following exchange illustrates the importance June attaches to how people speak to her:

> June (with dementia*): "…I think, when they think people's, what I've got, they think we are daft an' all. You know, 'awww you alright love, what happened'. I can't stand it, you know, Sarah* [her daughter] *doesn't treat me like that …she'll say 'here mother, just get on with it'. And she treats me like I want to be tret, not like a baby and 'sit there and don't move while I'm at work…' No she treats me like a grown up person… if they were all like her, people would be a lot better I think....If they were all like Sarah at the Dementia Societies, tret you like grown-ups, but it was very....*
>
> Sarah (daughter): *You don't know what they are like because you've not been*
>
> June: *No but they're patronising Sarah."*

4.8.2 Subtheme: Managing fear and anxiety

Whilst all participants appeared resilient some expressed their fears and anxieties openly, and others talked in more stoical or accepting terms. Some people with dementia and family

members expressed anxiety about what the future might hold. This subtheme overlaps with Theme 1 'adjusting life after diagnosis' as feelings of fear and anxiety affect how people adjust. This subtheme identifies how key relationships were - between people with dementia and family members and staff - to managing such feelings and encouraging uptake even when participants were fearful or anxious. The following quotes illustrate how Jimmy felt reassured by John, (his son-in-law) and how John felt the way the memory service staff member had interacted with Jimmy was key to reassuring Jimmy. Subsequently Jimmy had attended CST and maintenance CST. Here Jimmy and John explained Jimmy's response at being taken to memory services initially:

> Jimmy (with dementia): (crying) *I didn't want to go into a home.*
>
> John: *we had to ask...if* [staff name] *could talk to Dad first and explain to him that we weren't taking him to keep him, it was for an assessment to see if the courses and stuff were going to help. And after* [staff name] *spoke to him, he came out... he knew he wasn't staying, so he were like from walking like shuffling his feet and everything to a proper spring in his step... then when we said about going back the next time...he were waiting for me out here to go. But the first one it, he honestly thought that we were locking him up…*
>
> Jimmy: *Yeah because that's the only reason that they are wanting me to go to these places, is to assess me and put me away. My John says there's no way you are going to be locked away".*

Angela, Keith and Dot, all living alone, discussed limited contact, from their perspective, with their adult children, in terms which suggested that some of their family relationships were under strain. However, Keith also talked how his brother supported him, by generally attending medical appointments with him. Dot also clearly valued the support Jenny (her friend and neighbour and interviewed with her) provided, visiting every day and going on outings together. The following quote from Angela illustrates how she experienced family and friend's responses to her diagnosis:

> Angela (with dementia): *"Friends have not been present since… I told them* [about the diagnosis]….[tearful]... *I just I feel sorry for my daughter because she's had the brunt of my anger... she's doing the best she can… But she's staying away more these days... I said to her I don't get to see the children these days. And she brought* [granddaughter] *but* [grandson] *didn't want to come apparently..."*

In contrast, Beryl and Sue who both also lived alone talked about their children, wider family or friends throughout their interviews and described the support these people gave them. These solo interviews with people with dementia made me question whether Angela, Keith and Dot had family members or friends who could offer emotional support when they might be experiencing fear or worry, or to discuss and encourage possible interventions that could support them.

4.9 Theme 5: Unmet need and suggestions for services

I asked people with dementia what else, if anything, they would have liked to have been offered by services after diagnosis, or whether there were other activities they would like to be doing. I also asked family members if they would have liked anything else offered to the person with dementia or them both. Most people with dementia and family members said no to these questions and did not appear to expect anything else from services. For some this seemed to be because they felt supported by family and friends, were happy with their current routines and activities, or felt the impact of dementia on their lives so far to be manageable. For example, when I asked Kathryn if there anything else she would like to be doing, she responded:

> Kathryn (with dementia): "*I'm not really, to be honest I'm not really sure because there's so much, I seem to get myself into all sorts of things, I mean let's face it, the paper for a start we do all the puzzles between us don't we, know what I mean. So we are always doing something you know aren't we*".

Larry's response also suggested he did not want further interventions from services, when asked him if there was anything else he would like to be doing:

> Larry (with dementia): "*Not really. No....I'm happy with what I'm doing now*...*Yep. Quite happy.*"

Such responses may have indicated that people with dementia and family members found it difficult to consider their potential future needs or think about what else they could do, possibly this required a more abstract style of thinking, which may have been difficult given their cognitive impairments. Therefore, I suggested possible activities or interventions and gave tailored prompts to people with dementia and family members who had discussed particular difficulties. For example, I asked Steve and Jan if they would be interested in interventions aiming to support them manage Steve's shorter temper or memory difficulties. Steve replied he would accept anything that was intended to help him or Jan. I asked Larry whether he would like to meet other people in a similar situation but he and wife replied:

> Larry (with dementia): "*I'm not so much bothered about that. Meeting other people*
>
> Irene (wife): "*He likes his own friends and it's always been me that's gone out and met people...*"

When I asked some people with dementia, such as Dot, Edith and Sue if they would like support to carry on with activities they had previously enjoyed, such knitting, cake icing or sewing, they explained they could not do these activities anymore because of poor sight or difficulties with fine motor skills. The following quote illustrates the difficulty Dot had thinking

of other activities she would like to participate in and her decreased energy levels. When I asked Dot what else, if anything she might like to do or other support she might like, she replied:

> Dot (with dementia):*"No, not that I could do. Not that I could properly. No....one of my 10 is, gallop on a stallion across a beach. Oh I'd love that. And I had a chance to do it when I was younger...Yeah no I can't think of anything...No I don't think so. You know what happened, I tire myself out running off to do all these other things you know. In fact the sewing's becoming hard work"*

However, a few people with dementia and family members did talk about what support they would like or felt they needed and the way they had talked during the interview indicated to me some potential areas of unmet need. These topics are now presented.

Needs for support with emotions and coping after diagnosis

Angela said she would have benefitted from further support with her emotional and mental health. When I asked what else if anything, she would have liked from services she replied:

> Angela (with dementia): *"…Reassurance that my life didn't have to change immediately…I would have really benefitted because of the person I am, someone sitting with me after the diagnosis* [tearful] *and saying let's look at what you can do… Instead of that I came home with what I can't do… it was* overwhelming (crying)… *I could see my house going and everything just everything disappearing, being in a home. Wanting to commit suicide just felt totally abandoned. I don't think that was the intention but that's how it feels when you are given something like that, a diagnosis like that…"*

Steve (with dementia) said he would be willing to try anything suggested to manage his frustration and associated temper outbursts, if it might help him and his wife. Some of the accounts from other people with dementia indicated they also were struggling to come to terms with their diagnosis or with low mood, or appeared to have struggled with this in the past (for example, Keith, Beryl, Kathryn and Jimmy). This was also the case for some family members such as Linda, Irene and Steve who talked to me on the telephone when organising the interviews, or privately when the interviews had finished and they were seeing me to the door, about how their mood and challenges of coping the impact of dementia on their lives. Although these people did not talk about wanting support from services, but they did appear to have needs for support with their emotions or mood.

Needs for support with adjusting work related roles

All but one of the participants with dementia had retired by the time they had been diagnosed with dementia. Angela however, had still been working and she described being

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told she just had to stop. When I asked her what if any other support she would have liked, she replied:

> Angela (with dementia): *"I think support with work very much so. If I'd known, that I could have support with that and carry on working...But I felt left, I felt kind of right you've got your diagnosis now get on with it. Now I don't think that was intended but that's how it felt..."*

Another participant with dementia, Beryl, wondered about whether voluntary work could be a way for her to keep doing something interesting and meet people, as it had been in the past for her. It is not possible to know whether maintaining work related roles would be possible for these participants, but, their perspectives indicate that a work role of some kind was important to them. Thus, support to explore their options, consider the impact of losing these valued roles and whether they could identify and engage with new activities appeared as an unmet need.

Need for tailored interventions as well as groups

One family member suggested that their experience of interventions offered by memory services did not appear to consider individual needs and responses to diagnosis. Rather, existing group intervention programmes were offered, as she explained:

> Linda (wife): *"… But I think having these set programmes that, like they have at the memory clinics, we do this talk every 6 weeks and it's the same thing, I don't think they have much to offer because they are not individually tailored in any way..."*

Some people with dementia (such as June, Beryl, Tom, Larry, Kathryn and Steve) expressed reticence about attending group interventions. Some family members (such as Linda, Sally, Sarah, Phillip) also expressed doubts that the person with dementia they supported would enjoy or benefit from the group interventions offered. This may indicate unmet needs for stimulating and enjoyable activity for those people who did not want to engage with group interventions.

Needs for non-dementia specific or community based activity

People with dementia and family members talked about home based and community based activities that they had always enjoyed. Some of them talked about missing such activities as they felt unable to participate in them. This may indicate unmet needs for enjoyable activities people felt able to engage in. For example, Tom and Sally missed going to listen to live jazz but did not feel comfortable going out to venues in the evenings so they no longer did this,

Edith missed icing cakes and playing piano, explaining she had arthritis and limited space in her sheltered accommodation. Jimmy missed driving, which he had stopped since glaucoma affected his sight.

Others with dementia talked about having enjoyed day trips, holidays and, ideally, how they wanted to continue doing such activities. Some were managing to do such activities either independently or with support from family and friends. For example, Beryl described how she attended a community choir for years and often met friends in town.. Sue talked about day trips and holidays she had taken or that were planned with her pensioners club. Dot described attending her local church regularly and day trips she had been on with her friend. In the following quote Dot talks about how she liked to keep busy and another activity she had tried:

> Jenny (friend): *"...you've not been for a bit but she's goes to a sewing class.*
>
> Dot (with dementia): *Well my friend's, we went to a thing at the church, and we were at the library actually, and she said do you fancy looking at this patchwork thing in the library, I says yeah I do yeah. So you've just got to anything, or you are gonna finish up, you're gonna go crazy anyway..."*

Keith suggested that it would be nice to go the theatre with other people, when talking about activities he did with the Alzheimer's Society. Maureen (Mavis's sister) suggested that Mavis may enjoy meeting local people with whom she could meet and reminisce about the area. Several people with dementia and family members also talked about wanting to meet up with other people, get out of their home and be social.

The positive way in which most of the people with dementia talked about how they had, or still, engaged with activities which took place in their communities indicated a need for many of the people with dementia to be able to engage in community based, social activities designed for people with and without dementia. These accounts also suggested that some people with dementia (such as Keith, Dot, Iris, Tom, Sue) did need or may need support from others to do this.

Need for activities to stimulate cognition

When I prompted some people with dementia about whether they would like to attend groups involving quizzes or word games as a way of stimulating cognition most responded positively. Some were concerned about the level of challenge and their depleted sense of confidence was noticeable. This was the case for Steve, Dot and Beryl. The following quote from Beryl highlights the importance of offering activities that are at the right level of

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challenge for individuals. Beryl also makes clear that remaining engaged in her usual, non-dementia specific activities was important to her, as she explains:

> Beryl (with dementia): *"That would sharpen my brain up a bit wouldn't it, providing you could start off fairly you know not too hard…Yeah, as long as I've got a bit of spare time to still carry on with my interests"*

Liz (Edith's daughter in law) questioned why they had only been given information about activity groups after diagnosis and not during the diagnostic process for vascular changes, which had taken over a year. Liz questioned whether Edith could have benefited earlier from the routine of social activity they established after the dementia diagnosis had been given, and when they had been told about various group interventions. This account suggested there may have been a need for advice about activities and keeping stimulated, prior to diagnosis, for Edith and her family.

Needs for support with physical exercise, mobility and balance

Most people with dementia, said they would be interested in interventions offering physical activity or exercise, when prompted by me to consider this. The following quote is from Larry (with dementia); when I asked if he would like support to keep physically active replied he would:

> Larry (with dementia): "*Yeah, they talked about it about it when I went to [name of exervice group]. I might be considered for that.*
> > [Becky Field (researcher): *You'd go if that were offered?*
> Larry: *Yeah"*

However, there were exceptions to this view and people with dementia who felt their physical health was such they would not be able to tolerate it said they would feel unable to take part in much physical exercise.

Interventions for people with vascular dementia

Irene (Larry's wife) talked about the lack of contact with memory services since he had been diagnosed with vascular dementia, explaining that they had been told memory services would not see them again:

> Irene (wife)*: "... I know it's one that they can't treat, this vascular you know and so obviously it's going to get worse, so I would have thought... they'd have wanted to*

know how he's progressing.. I don't want to complain about it, but I just think that's what I thought they would have done so…"

This account suggests there may be a need for more interventions appropriate for and aimed at people with vascular dementia, although Larry himself said he did not want to attend anything else other than the exercise group he went to.

Support for people with dementia without family support to attend interventions

Of the six of the people with dementia who lived alone, Sue and Edith described having support from family and friends to travel. Angela, Beryl, Keith and Dot were currently able to travel independently but it was unclear if they were to become unable to do this how they would still be able to attend interventions if they wished to. Also, most of the joint interviews indicated that most of these people with dementia relied entirely on family members to support them attend interventions, so if those family members were to be unavailable, engagement with interventions would be difficult or impossible. For example, Edith attended several groups, which she talked about really enjoying. Edith was driven by her daughter-in-law and/or son (Liz and Colin). Liz had talked about how retiring recently meant she was able to support Edith as needed. The following quote illustrates Edith's reliance on family and considering independent travel made her uncomfortable and would be a barrier to her engaging with any intervention outside the home:

> Edith (with dementia) "*I can't go on a bus anymore, I used to go to* [names a place] *every Friday, I've not been for years*
>
> > [Becky Field (researcher): *What do you think stops you Edith?...*]
>
> Edith*: Well I think it's we just that er I were a bit frightened I mean because...*
>
> Colin (son:) *You were worried about getting lost I think you said...*"

Thus although people with dementia and family members did not explicitly express a need for support with travel for themselves in their current lives, there appeared a need for support for people with dementia without the confidence or ability to travel independently to continue to engage with interventions, if they did not have family able to support them attend interventions.

4.9.1 Subtheme: Living as well as possible with dementia

I asked all participants how they would advise other people living with dementia and their family members to live as well as possible. Not all people with dementia or family members answered this question and some said they would not want to advise anyone else as

everyone was an individual. The following quote from Mavis illustrates this kind of response:

> Mavis (with dementia): *"I wouldn't tell them how to spend their time, I mean, everybody's got their own way of spending their time, their own, their families and or friends or, or I mean if you always keep in touch with your family..."*

Those people with dementia that did answer (such as George, Sue, Tom, Dot, Mavis, Pam, Larry, and Edith) talked about the importance of maintaining regular social activity, keeping occupied with enjoyable activities, taking up offers of intervention and the importance of family and friends. The following quotes illustrate such responses:

> Sue (with dementia): *"Go out. Get out with people. If you've got a friend that will go out with you, get out."*

> Mavis (with dementia): *"Well whatever's available to them to get, to get involved with that. You know it might be through their family, or through any clubs they've joined or I mean I've done loads of things really haven't I…."*

> George (with dementia): *"...I would say just carry on as you were because I don't, I don't really feel any different apart from some days I do get more forgetful... you might feel a little bit depressed to begin with, but if you go along to some of these gatherings or groups, I think it would help you enormously."*

> Dot (with dementia): *"You've got to ask for it, you've got to ask for advice....I'd tell them to tell everybody. Tell everybody then when you do something stupid, you go, you know, you know when you've said something stupid and you think whatever did I say."*

> Larry (with dementia): *"Get someone as good as what my wife is to me…Yeah that's what I'd say… Somebody caring, that's going to give you that love and attention."*

Chapter Summary

This chapter presented key themes from the interviews held with people with dementia and their family members. Adjusting to a diagnosis of dementia and self-awareness, the appeal of interventions and perceptions of benefit, the context of services and the relationships between people with dementia, family members and staff all influenced acceptance or rejection of interventions. The next chapter presents the findings from interviews held with staff working in dementia services.

Chapter 5 Findings from interviews with staff

This chapter presents findings from the interviews and focus group held with staff. Staff were asked about their experiences of offering interventions, responses they encountered and their thoughts about why people with early dementia may accept or decline interventions. First, the outcome of the sampling and recruitment process is explained and characteristics of staff who participated described. Second, the main influences on uptake of interventions are presented as four key themes.

5.1 Sampling and recruitment

A convenience sample of 12 staff was obtained. One medical consultant and one registrar doctor working with Memory Services 1 were approached via email and telephone but did not respond. I recruited a doctor from Memory Service 2, via personal contact with the research nurse from that service. Nine staff were recruited from Memory Service 1 and two from a local branch of the Alzheimer's Society in Location 2.

5.2 Description of participants

Participants included Occupational Therapists (OTs), Nurses, Support Workers, Managers, a Psychologist and a Doctor. Ten staff were female, two were male. The range of time staff had worked in their current posts ranged from 12 months to 10 years. Participants were working at different levels of seniority. All participants worked directly with people with dementia and their families. For the managerial staff, their jobs also involved direct contact with people with dementia and families. Table 5.1 presents the number of different types of staff participants, and the settings they worked in.

Table 5.1 Type and number of staff and work settings

Type of staff	Number of participants	Work setting
Occupational Therapist	3	Memory Service 1 and 2
Nurse	3	Memory Service 1
Support worker	2	Memory Service 1 Alzheimer's Society
Service Managers	2	Memory Service 1 Alzheimer's Society
Psychologist	1	NHS older adults mental health services, worked with Memory Service 1
Doctor	1	Memory Service 2

5.3 Types of interview completed

One focus group took place. This involved seven staff (three nurses, two OTs, a support worker and the manager who joined the group for the last 15 minutes) who worked together at Memory Services 1, and was made up of staff working that day.

Seven semi-structured interviews took place. Four staff were interviewed individually face-to-face or by telephone (the memory services manager who completed both an initial interview and another interview, one OT who completed the pilot interview, the psychologist and the doctor). One face-to-face interview involved two people, who were colleagues at the Alzheimer's Society. Table 5.2 summarises the different types of interviews, the number and type of staff completing each interview.

Table 5.2 Number of different types of interview and number of staff completing each type

Interview method	Type of staff	Number of staff participating	Number of interviews
Pilot interview face-to-face	Occupational Therapist	1	1
Initial interview telephone	Manager[1]	1	1
Individual face-to-face interview	Clinical Psychologist	1	1
Paired face-to-face interview	Alzheimer's Society staff (1 manager, 1 support worker),	2	1
Individual telephone interview	Manager[1], Doctor	2	2
Focus group	Nurses, Occupational Therapists, Support worker, Manager[1]	7	1

[1]This manager was the same person; they also joined in the focus group towards the end

Location and duration of interviews

As staff were given the choice about the mode of interview, locations varied. The pilot interview was conducted at the OTs home. One interview was held at the member of staff's office and one held in an office at the University. The focus group took place at the Memory Services 1 building. The staff who gave telephone interviews were speaking from their office telephones. The shortest staff interview was 30 minutes, the longest an hour and 17 minutes. The focus group lasted one hour.

For the initial interview with the memory services manager I took hand written notes. All other interviews were audio recorded. The data from the pilot interview and the initial interview with the manager was included in the analysis.

5.4 Findings from thematic analysis

My analysis found that during the focus group all staff spoke, although two nurses spoke more than others. I found there were no significant disagreements within the group and agreement was demonstrated by nodding and murmurs of agreement from other group

members when one member was speaking. I tried to prompt discussion and debate within the group by asking participants what they thought about particular statements one of them had made and by trying to ensure all had the opportunity to speak.

During the focus group, I was unable to cover all questions in the topic guide and did not ask about types of support or other interventions they might consider appropriate. This was because I needed to keep to the one hour agreed (which involved taking consent as well discussion time) as staff needed to return to work.

The paired interview with two members of Alzheimer's staff involved a manager and support worker. The manager spoke a lot more than the support worker. The manager openly acknowledged that they had a tendency to talk a lot and I did find it difficult to try and ensure both people spoke relatively equally. However, I found that support worker was able to express their views within the interview although they did talk less than the manager. The individual interviews were conducted as planned.

Interventions described by memory services staff

During the initial interview with the manager of Memory Service 1, they explained this memory service had a dedicated team, including an OT and support workers, to provide a rolling programme of CST groups. These CST groups were offered to people with mild to moderate dementia and a family member, or people with dementia alone. The manager also explained the service offered a weekly exercise group run by a physiotherapist and an OT together, for people with vascular dementia to improve their balance, strength and confidence. The manager also reported a carer support group and a group for people with young onset dementia were provided. The focus group staff, psychologist and second interview with the manager confirmed that the CST groups ran over 14 weeks. These staff said CST groups tended to be offered at post-diagnostic appointments with a memory service nurse. They also described regular monthly maintenance CST groups, for people with mild to moderate dementia and their family members, or people with dementia alone. These groups were held in different community venues and at the memory services building. The focus group and interviews with the manager were dominated by discussion about CST, as opposed to other types of psychosocial intervention. Thus the interviews and focus group held with staff from Memory Services 1 indicated that CST was the most common psychosocial intervention offered there. However, the OT taking part in the focus group mentioned they visited people at home at different points after diagnosis, suggesting that some people with early dementia were also offered occupational therapy. The psychologist discussed other psychological interventions they provided such as tailored cognitive

rehabilitation for a person with dementia and a family member and cognitive behavioural therapy, as well discussing the CST groups run by the CST team.

The doctor from Memory Services 2 explained that the first intervention they offered to people after diagnosis was an education and information group, run as a workshop, by the OT team within that service. It generally ran weekly over four weeks. The OT who had previously worked at Memory Services 2 explained that that service provided CST groups and support groups, both for people with dementia and their family members. This OT also talked about providing tailored cognitive rehabilitation for people with dementia and a family member and working with people with dementia in their own homes to assess and manage safety and risk concerns such as eating out of date food.

Staff from both memory services described an information pack being given to people with dementia and families either at diagnosis or post diagnostic appointments. This pack was described as containing leaflets and written information about dementia, about support services and interventions offered by the memory service.

Interventions described by Alzheimer's Society staff
The Alzheimer's Society manager explained how their staff offered individually tailored support to identify what the needs of people with dementia and family members might be and what kind of support they may wish for. Both of the Alzheimer's Society staff also talked about different peer support groups offered. These included a post-diagnosis group, a men's' group for people with dementia, drop-in memory cafes that people with dementia and family members could go to, run monthly in different community venues across the city and 'Singing for the Brain' sessions which involved a choir like singing session for people with dementia and family members. The support worker also described a telephone befriending service. These staff also referred to a self-management group and a support worker post with the specific remit to support people who lived alone or without regular family support These two interventions had been offered previously but were no longer provided.

Thus with some exceptions, the kinds of interventions most described by staff were group interventions.

Four key themes, identifying issues affecting uptake of interventions by people with early dementia, from the perspectives of staff interviewed, were identified. These were:

- Theme 1: Service contexts and wider society
- Theme 2: Individual characteristics

- Theme 3: Communication and relationships
- Theme 4: Unmet needs and ideas for service developments

The themes, with subthemes and illustrative quotes are now presented. When referring to staff views or experiences the pronoun 'they' is used, to maintain confidentiality.

5.5 Theme 1: Service contexts and wider society

Theme 1 is concerned with how differing service contexts influenced the types of interventions available offered by staff. As described in Section 5.4 above, various interventions were described and the process of offering interventions was influenced by the service in which staff worked. The impact of limited resources within dementia services was also discussed. Three subthemes were identified: 'Different types of intervention to encourage engagement with services' 'Accessing interventions and practicalities' and 'Societal influences'.

The process of offering interventions in memory services

Staff who worked in both memory services explained that people with dementia were generally first referred to memory services by a GP. A dementia diagnosis was given by a doctor after an assessment process, usually involving a combination of interview, CT scan and neuropsychological testing. The focus group nurses talked about how they provided post-diagnostic support appointments. These appointments were explained as one hour long, taking place approximately six weeks after a diagnosis had been given. During the focus group the nurses agreed that explained the aim of these appointments was to find out how people were coping and signpost them to sources of support (for example, the Alzheimer's Society, carers support or other community based organisations). They would make referrals if necessary and if consent was obtained from the person with dementia and family member (for social services, for example). Nurses also reviewed medication and any related concerns during these appointments. The nurses also talked about trying to discuss the information pack with the person with dementia and family member. The nurses explained they would refer people to the CST group if they had mild to moderate dementia and the person with dementia consented to this.

Focus group participants agreed that once a person had been referred to a CST group, a member of the team providing CST would make initial contact with the person by telephone, and then send an invitation letter.

The doctor from Memory Service 2 explained how they their role was focused on giving a diagnosis and prescribing medication, although they tried to talk about psychosocial

interventions as well. The following quote highlights how they felt they needed to prioritise what was discussed, within their role as a doctor:

> *"....yes I think psychosocial interventions are important and should be as important as medication but....on the one hand yes we can give you this medication and this treatment and also we can help you with some education and you know looking further at the diagnosis...in the scheme of things it's more important as a medic that I communicate the medication. Probably...I know I ought to be doing both... ...in our half hour we're also doing things like mood reviews we're talking about driving in dementia, talking alcohol issues there's a heck of a lot to get through and I think I personally I tend to weight things so the important thing is that I've got across the assessments, the diagnosis and the treatment and then if I don't get any further then..."* (Doctor)

The doctor also explained within their half hour appointments they also had to write a summary letter. This doctor said if they had been unable to discuss the education and information group, due to other issues taking precedence within the appointment, they knew that psychosocial interventions would be discussed at a subsequent six week post-diagnostic appointment with a memory service nurse, and an information pack provided then.

The process of offering interventions in the Alzheimer's Society

The Alzheimer's Society staff described a different service context. They both explained that people with dementia and families could refer themselves or be referred by health professionals. They agreed that initial contact was most often made by telephone. The support worker explained how the process of initial contact and identifying potential needs for intervention in the following way:

> *"....generally we would perhaps ask if somebody wants a one-to-one, face-to-face and that could be by home visit or people can come in to the office but we don't have a private space. And from there to find out really I suppose what it is that the person is needing, what their problems are at the time. So it's generally very person centred I suppose. It's not a very prescriptive role in that sense like an OT, physio etc. We're never quite sure you know who's going to present and what the problems are really."*
> (Support worker, Alzheimer's Society)

These staff said that offering interventions happened during conversations with the person with dementia and family members about support they might need and want. These conversations aimed to be responsive and tailored to the individual, aiming to link people with local services or interventions that might meet their needs. Interventions offered could be those provided by the local branch of the Alzheimer's Society itself, such as the memory cafes, 'Singing for the Brain' or peer support groups, or those provided by other organisations, such as a community gardening groups or lunch clubs. These staff said they may also make referrals to social services or recommend interventions offered by NHS memory services, depending on people's needs.

Commissioning and financing of dementia services

The impact of resource management within services was raised by both managers, the psychologist and the doctor. They talked about how competing priorities within services affected the type of psychosocial interventions offered. The doctor questioned the value placed on psychosocial interventions and whether prescribing medication may be perceived as cheaper, as the following quote illustrates:

> *"...I guess part of it comes out of, not the value you give to psychosocial interventions but...something to do with...maybe the sort of financial weight in the organisation of psychosocial interventions...psychosocial interventions are great but it's like anything that involves a lot of time and sort of highly trained people, it's expensive... medication is cheaper that's why so many people are on antidepressants and don't get IAPT'd[1]* and it's the same thing really in that...What interventions do we have and how accessible are they and who are they going to help anyway?...the people that are more motivated often are the people [who] are going to benefit highly from almost any healthcare…"* (Doctor)

The psychologist talked about how the service they worked for had had to prioritise providing early diagnosis to meet expectations of NHS commissioners and that developing interventions for residents with dementia in care homes had also been prioritised. The psychologist acknowledged early diagnosis and care home interventions were important and necessary. However, the following quote illustrates how the psychologist also considered this had impacted on their ability to further develop interventions, in addition to CST, to support people with early dementia after diagnosis:

> *"...our managers...they are kind of stuck aren't they between having to meet the needs of what the commissioners are saying is important and what we know is important to the people using the services... in the last few years the push has been around early diagnosis, increasing diagnosis rates... now a 6 week target to diagnose people. So all the resources get invested there. And the way that the service is measured in terms of the outcomes to the commissioners, is on how many people we're getting diagnosed, not on what happens afterwards... So whilst that's been driving it, and we've been saying, 'well do you know what, what about when people do get diagnosed what are we offering that's of any benefit?'....It's been kind of difficult to get them to allow us to put the time into developing that..."* (Psychologist)

Both the psychologist and focus group participants reported a recent initiative within location 1 trialling diagnosis within primary care settings, for what was described as 'non-problematic Alzheimer's or Vascular dementia'. These participants considered that such a diagnostic route may be limiting uptake of CST because of limited referrals received via this route, compared to those diagnosed within memory services. The psychologist questioned how

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[1] IAPT stands for 'Improving Access to Psychological Therapies', which is how this doctor is referring to psychological interventions within the NHS

GPs may promote CST and respond if people declined. The following quote illustrates some concern about the perceived impact of this service development on intervention uptake:

> "…we've got a substantial number of people that are now diagnosed in primary care, once they've said no [to CST] I've got no idea if they are being re-offered anything at all. My gut is that they're not…So there's…a really big cohort of people that we now no longer even as a specialist service have any influence over and there's such a lot of work to be done with the GPs because they are very much indoctrinated into the world of donezepil and memantine…they could tell you anything…about titration rules but if you go and ask them about CST is or anything they'd be really struggling to tell you about it. So, yeah." (Psychologist)

Both the Alzheimer's Society staff discussed how financial considerations affected what their service was able to offer. The manager talked about how they tried to meet the diverse needs of people with dementia by supporting development of interventions provided by other, local community based organisations, particularly given the limitations of funding. The following quote illustrates this approach:

> "…we get approached by other organisations... interested in running a fitness class for vulnerable people and we've considered people with dementia…what would you need to run dance group for people with dementia. So you know, gym sessions, all sorts of things...all the time considering how we work with other people to come up with really creative ways of capturing what it is that people need...resources are always going to be, you know if money was no object we'd have a team of 20 people." (Manager, Alzheimer's Society)

The Alzheimer's Society support worker also described how they had previously been able to support people who would not engage with groups by using a council provided service, although it was unclear if this would have been for people with early as well as more moderate dementia. The following quote illustrates this person's concern about the impact of council service cuts:

> "It's also the fact that some services have gone. When I first started I referred to like sitting services... if somebody wouldn't go out to a group then there was a sitting service... I mean yes you can buy in companionship calls...twenty pounds an hour, but that, these were funded by the council so for someone who wasn't a group person... could get a sitting service instead." (Support worker, Alzheimer's Society)

Also the way their local branch had previously tried to support people with dementia who lived alone to engage in activity outside their homes was no longer possible due to funding constraints, as explained in the following quote:

> "... if let's say it was somebody who was by themselves, we have in the past said right, well, the café's on Friday … this…was within that person's [a staff member] role and the remit…they would go and pick them up and bring them to the café. We don't have the level of resources to be able to facilitate that ..."

(Manager, Alzheimer's Society)

Communication between staff

Interviews with the doctor and psychologist indicated that how staff communicated with each other about psychosocial interventions was influenced by the systems and requirements of the services they worked in. For example, the doctor said that there were team meetings to facilitate awareness of service developments, including interventions offered, but they personally did not always manage to attend these. When I asked the doctor what might influence them to refer or signpost people to psychosocial interventions, they replied:

> *"Hmm, that's a tricky one... if you're in touch with people closely who do provide interventions then you've got better feedback on how it's going and all that sort of thing... being...reminded of what's going on and trying to find the, the best intervention if you like....for that particular patient. Or to remind you to talk about interventions...that probably comes into the governing meetings...I don't always get to those because I'm busy with the clinic or busy with research or whatever.......having said that the OTs work...opposite...so physically I'm very close to them but quite how much we talk about these issues, I think communication could be better."* (Doctor)

The psychologist explained that cognitive behavioural therapy (CBT) for people with early dementia experiencing depression or anxiety was an intervention that they as a psychologist, could offer. However, they were unsure if this was considered as an option by other staff within the memory service who were in a position to refer suitable people to them for such intervention. The psychologist recognised that they had not discussed it with these other staff.

5.5.1 Subtheme: Different types of intervention to encourage engagement with services

All staff recognised that some people with dementia could struggle to engage with services and may reject intervention offers. The focus group agreed that this could be because some people had difficulty adjusting to a dementia diagnosis or may be unable to recognise symptoms. The occupational therapist, doctor, psychologist and Alzheimer's society staff also talked about these issues. The focus group and Alzheimer's Society staff talked about how people's lives may be unsettled or how people with dementia or family members may experience poor mental or physical heath. Different types of interventions offered seemed to be regarded as a way that services could try to meet the differing of needs of people with dementia, at different times after diagnosis and when people felt ready to accept interventions offered, although the choice of interventions described by the focus group participants was limited to CST, the information pack and occupational therapy home visits.

Staff explained how group interventions such as CST or an education and information sessions were offered after people had been given the information pack. These groups demanded commitment and regular attendance such as a CST or education and information group. Focus group participants agreed that people with dementia could feel overloaded, especially given the amount of information covered within post-diagnostic appointments. Information packs were seen as one way to respond to this as highlighted by this quote:

> "…we do provide an information pack, to go home with…because we're aware that a clinic appointment can be very overwhelming, it can appear like white noise, you know they can hear a diagnosis and 'I might have to stop driving' and that's all they get so it's often helpful for them to digest that information and also circulate it round family and our contact details…" (Nurse 3, focus group)

The doctor also acknowledged that people with dementia could feel overloaded during appointments, and information was given for people to take home and read in their own time. The doctor talked about the need to manage the amount of information offered, given how people with dementia coped with the amount of information given during their diagnostic appointment, as the following quote illustrates:

> "...essentially my role is to mainly...giving diagnosis...usually I would go on to talking about the information pack, very briefly...I don't usually go into lots more detail about other psychosocial interventions because we just don't have time and actually they've had so much information by then that their brains are just… so it's in the pack, most of it." (Doctor)

Alzheimer's Society staff agreed that their service aimed to provide different types of intervention, depending on what individuals needed or were ready to accept. 'Drop-in' groups were offered (such as the memory cafés and 'Singing for the Brain') as well as peer support groups offered to people staff identified as being likely to benefit from such groups. They explained staff would identify these people as those wanting to talk about the impact of dementia on them and appearing to have the cognitive abilities to engage in such groups. Telephone befriending was also provided as another way to try and engage people who may reject other interventions offered.

5.5.2 Subtheme: Accessing interventions and practicalities

Transport and travel

Transport and travel were regarded by all staff participants as greatly influencing people's ability to attend interventions and their willingness to engage in them. Transport was not generally not provided for interventions offered by either memory service or the Alzheimer's Society. However the psychologist said transport could be provided for their sessions and the memory services manager said sometimes they provided transport 'under the radar' if needed. This was felt to facilitate uptake and lack of transport provision to discourage uptake, especially as memory services covered large geographical areas and some parts of the locations were not served well by public transport. The psychologist talked about how daunting it could be for people with dementia and family members to try and travel to interventions given the distances or if the trip involved two buses, which was possible for those living on the periphery of the catchment area. If people with dementia or family members had mobility or other health issues affecting their ability to travel, then several participants suggested that the effort, cost and potential stress of arranging transport could discourage people from accepting interventions. The following quote highlights this:

> *"...if people are not physically able to get out of the house that's going to be obviously an issue, and get transport. There's no transport to those psychosocial interventions that's provided. That's quite a major deal I would say, if there was transport maybe more people would go."* (Doctor)

Staff accounts suggested that people with dementia were often dependent on family members to bring them to intervention sessions as many could not or would not make the journey required independently. One of the nurses in the focus group also suggested that some people with dementia worried about burdening their families and refused interventions partly because of this.

Venues

Types of venues were also regarded as likely to influence responses to interventions. Staff from Memory Services 1 described CST groups being offered in community venues, as well as at the memory service base, as one way of trying to encourage uptake. The Alzheimer's society manager questioned whether using church halls as venues may deter some people from engaging with what was offered there. The Alzheimer's Society support worker wondered if hospital based venues and a clinical atmosphere could discourage uptake of interventions that were aiming to support people live with dementia, as explained in the following quote:

"…just the actual physical environment as well is really important, if you're in the hospital it, people, and I, want to get out of hospital. I don't want to be in a clinical environment to necessarily you know do an activity or a workshop or whatever."
(Support worker, Alzheimer's Society)

Duration

The doctor was the only person to discuss duration of interventions, questioning whether length of interventions could discourage uptake, as illustrated by following quote:

"I mean we try, most of the doctors I would say, try to talk about psychosocial interventions at least in terms of...[uses name of the information and education group sessions] *course and possibly this* [uses name of a group intervention research study] *I have slightly gone off talking about* [group intervention research study] *... because so many people say 12 weeks is too much..."* (Doctor)

The doctor also highlighted the challenge of trying to meet needs of both family members and people with dementia when offering group interventions. The doctor explained that longer interventions could be difficult for family members who worked but having interventions, such as the education and information group, run on one longer day may not be appropriate for people with dementia with attention, concentration, fatigue and memory difficulties.

5.5.3 Subtheme: Societal influences

Influence of the media

The Alzheimer's Society manager was the only person to talk about how media coverage of dementia (such as a 'dementia tax' or potential treatments) or the language about used dementia more widely influenced the concerns of their service users. This manager felt this subsequently influenced the conversations staff could have people with dementia and impacted on how able staff were to talk to people about topics or interventions that may be of benefit, as explained in the following quote:

"...you can often lose some of the other essences around… things that might benefit actually towards living a little bit safer or feeling a bit more confident…for a period of time all the calls were about dementia tax…. about this medication that I've heard about, you know the Daily Mail have said this…the way in which the media uses dementia as a tool of ...fear and rejection we're often fielding and encouraging people, to actually say it isn't about suffering we don't recognise that as a term in the society, so you know what we want you try and think about is this, this and this and this. Trying to strengthen people's kind of like resilience about how they feel about themselves being a person living with dementia." (Manager, Alzheimer's Society)

Stigma

The impact of stigma on people's willingness to engage with dementia services was discussed by the memory services manager, the occupational therapist interviewed individually and the Alzheimer's Society staff. These staff indicated there could be a reluctance to attend appointments or interventions and that such feelings were at least in part related or exacerbated by the stigma experienced by those with dementia. The following quotes illustrate this:

> *"…they'll say we don't want to be with other people with Alzheimer's and we haven't told anybody that you know my wife's got Alzheimer's…we don't want people knowing that she's got it so we don't want to be going to places like that...You know but there is still a lot of people who do feel that there is this stigma attached to that diagnosis."* (Manager, memory services)

> *"... some people I think essentially feel a stigma around attending memory service and obviously that depends as well on where it's where it is and sometimes it can be based in a building with other services that may not be quite as obvious. You know people are perhaps worried about being seen..."* (Occupational Therapist, individual interview)

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5.6 Theme 2: Individual characteristics

Theme 2 is about influences on uptake which staff ascribed to people with dementia and family members, as individual people or couples, as relating to personal characteristics or qualities. This theme is presented as three subthemes about the different kinds of characteristics attributed to people with dementia and their families and perceived as likely influences on responses to interventions, particularly the group interventions staff described their services as offering.

5.6.1 Subtheme: Impacts of dementia on individuals

Adjusting to diagnosis and mixing with others with dementia

All staff acknowledged that people with dementia and family members needed time to get used to the diagnosis and that this adjustment process influenced some people to reject interventions. The psychologist explained their view about this in the following way:

> *"...you'll certainly have people…when we give the diagnosis it's just not the right time for them, sometimes they don't want to start the donepezil just yet either…they want time to go away...can take months of just, just making their own adjustments at home before they feel ready to do anything else, it's just too threatening to come to any type of groups at that time. Because actually when they come into that group, they look around and it mirrors back the thing they are sort of wanting to sort of defend against at that particular point in time. And I think some people make that adjustment quite quickly and others don't make that adjustment and they're often the people that need the adjustment kind of work."* (Psychologist)

Focus group staff agreed that reasons for rejecting CST groups could be related to how people were adjusting and worry or discomfort about mixing with others with dementia. The following exchange illustrates some of these concerns:

> Nurse 1: *"I think people have a perception of Alzheimer's Disease and the progression of the illness ... don't necessarily want to know about what happens in the later stages of the illness and the fear that when they go to these groups they are going to be sat there and they're not going to be able to converse or interact with other people in the group. Errm. So that puts a lot of people off….*
>
> Support worker: *I've experienced in groups where somebody's not been so far along with the dementia where somebody's come to the group and…you can see the anxiety on people and you can see them actually thinking 'am I gonna be like that'… and it actually puts them off coming to groups."*
> (Focus group)

The memory services manager recalled how previously the service had run an education group for people with dementia. They reported the feedback from people with dementia and families had highlighted the challenge of providing this intervention for people with dementia of different ages, from example 65 years to those in their 80s or older. Some of the younger people had had expressed feeling scared or angry about having dementia when they had only just retired whereas people in their 80s who were attending the same sessions had had many more years of living life without dementia. These accounts, from different staff suggest there was a consensus that some people with dementia may not consider being in a group with others with dementia likely to be a beneficial experience for them, and may reject such interventions because of this.

Reduced motivation

Reduced motivation or ability to initiate activity were identified by the nurse, the occupational therapist in the focus group and the doctor as symptoms of dementia often encountered and to be expected. These staff felt such symptoms could inhibit intervention uptake. The doctor's view suggested that they thought some people may prefer to take medication, rather than engage with psychosocial interventions, although they talked about this being particularly the case if apathy were a feature of their dementia and they were moderately affected as the following quote illustrates:

> *"…some... people who actually just can't be bothered possibly because their diagnosis is at the moderate stage and their apathy is quite marked and so actually they're not really bothered. You know I'll take the treatment [referring to medication] but I'm not really interested in doing anything else. …"* (Doctor)

The following exchange in the focus group illustrates the challenges this experience presented to these staff when trying to encourage uptake:

Occupational Therapist: *"…there's a lot about motivation, when…at any stage in dementia, err that I don't fully understand, that when you are not remembering, that you,..need a cup of tea or a meal, or that it's good for you to go out and meet people, you just get more and more demotivated, as you do it less, so, and that alongside insight, just, people don't think they need to go out or…forget they haven't gone out of the house for two weeks or…*

Nurse 1: *to be honest that is one of the biggest symptoms of dementia, is that people do become more apathetic, so that motivation to do things, which is obviously…we're trying to work against that in some ways you know."*
(Focus group)

Insight and self-awareness

Some staff used the term 'insight' to describe people with dementia's awareness or ability to acknowledge their diagnosis, impairments or difficulties. This issue was discussed by focus group participants, the psychologist, doctor and Alzheimer's Society staff. These participants reflected on their experiences of working with people who had demonstrated limited self-awareness, which in their view had led to rejection of interventions. The psychologist talked about the difficulty of trying to distinguish between neurologically based impaired self-awareness due to the disease process damaging parts of the brain and protective psychological mechanisms related to emotional adjustment, as the following quote illustrates:

"...that subtle difference between neurological based insight or awareness …the frontal stuff, we know that, that kind of self-monitoring, self-awareness, versus that psychological defence…it's really hard to tease them apart sometimes. But I think that psychological stuff, it's that warding off isn't it, we ward off the reality of the diagnosis and what it means for us in the future…And I think when somebody's stuck in that warding off place as well, they'll filter what you say to them anyway, they'll filter in the stuff that says no this is just normal aging... the stuff that's about being dementia just gets, it doesn't even get processed a lot of the time." (Psychologist)

Participants from the Alzheimer's Society talked about how, if a person with dementia did not acknowledge their diagnosis or a need for support and declined their service, they could work with family members as service users in their own right. The following quote highlights the challenge presented by offering interventions to people with dementia who may not acknowledge their diagnosis or difficulties:

"…often people we support do have insight into the illness. But a lot of people don't have the insight, even in the early stages are saying there isn't a problem there…makes it very difficult to know how to help the carer and the person with dementia...it makes it very much easier if that person is aware… …I suppose we are working more probably with the carer in that respect really, rather than the person with dementia." (Support worker, Alzheimer's Society)

Reduced confidence

The psychologist, the occupational therapist interviewed individually and one of the nurses in the focus group discussed how attending an intervention group for the first time involved meeting new people, potentially in a new place or carrying out unfamiliar activities. These staff did not talk about this in relation to non-group based interventions (such as interventions aimed at the individual or dyad). The reduced confidence and self-esteem experienced by some people with dementia, particularly in social situations were regarded as discouraging uptake. The following quote illustrates this view:

> *"It's such a common disposition, to fear, meeting new people... diagnosis of dementia, that makes you so much more insular err you lose that confidence, that ability to communicate fluently, you just, it's like the polar opposite to what you feel is gonna be helpful for you… that's a real significant challenge, meeting new people."* (Nurse 3, focus group)

Too early or busy living life

The staff in the focus group also described situations in which some people with dementia and families declined interventions by saying they were managing okay, or they it felt it was too soon, that they were not experiencing major difficulties or that they had busy lives with other responsibilities. These staff thought such people did not perceive a need for the interventions offered. In the focus group for example, participants discussed why people rejected CST, and identified that some people with early dementia they saw were carers for grandchildren or reported active social lives. Some of the nurses in the focus group considered if people with dementia and family members understood CST to be offering social interaction and stimulation, they may question the value of that if their lives felt busy enough or felt their social networks and routine of activities to be established and busy, as the following exchange illustrates:

> Nurse 2: *"Some people with the groups though, especially in the mild stages, they're just too, they've got a lot on, haven't they*…{others: *yeah*}...*they might be babysitting for grandchildren, there be may other social things that they're doing, so for some people they feel that they're life's full anyway, so at that point they haven't...haven't got time*
>
> Nurse 3: *yeah …. they're seeing it as social stimulation aren't they? So why do I have to...they see it generally as social stimulation so why do I need all these extra new people when I've got quite an active…*{others: *active social life… yeah*}*"* (focus group)

5.6.2 Subtheme: Individual personalities and personal background

Individual personalities

The manager of memory services, focus group participants, the occupational therapist interviewed individually and Alzheimer's Society staff accounts all indicated they had experience of people declining interventions because people with dementia did not want to participate in a group. They talked about how some people with dementia described themselves or family members described both or one of them as not 'the kind of' people who joined groups. The manager talked about how uptake of a group CST could be influenced by people's pre-dementia personalities and that in their experience some people with dementia made statements like 'oh I've never mixed with people' or 'no I'm not one for groups, I'm not interested in that, you know I'm not a mixer'. The occupational therapist, the Alzheimer's Society staff and memory services manager shared experiences of running groups, recalling both positive and challenging aspects of group interactions. The occupational therapist reflected that although services ran group interventions it was uncertain whether the experience of attending a group would be a positive or negative experience for an individual, as the following quote illustrates:

> *"...some people simply aren't group people and...I think...of course we think groups are great but it's just not for everybody is it. Either because they are not, they are quite shy and inhibited or not particularly sociable or... some people find it a bit patronising just being in a group. Or simply there's more uncertainty with groups as well. Now obviously it can work both ways...I know people who've been to groups...'when I first came here and I looked at you and de de de' but then they're because of what they've discussed during the group they've really, they've really bonded...that is an issue, the uncertainty you don't know..You'd want to think that you'd...share....profound information or just useful information together and...kinda of...you know connect with people and potentially make lifelong friends...but there is absolutely no guarantee of that. So just in terms so what can this group offer...that might happen you don't know, it's the uncertainty isn't it."* (Occupational Therapist, individual interview)

Focus group participants agreed that individual personality was part of why some people rejected CST groups and agreed this kind of response had to be respected, rather than challenged or persuaded. The following quote illustrates this view:

> "…*I think the biggest factor we haven't mentioned in attending groups is people's personalities, so it doesn't matter what age you are or what condition you've got some people [who] just don't like mixing within a group setting so…* {murmurs of agreement from the group: yeah yeah} …*that's probably the biggest thing that I find, that people say 'oh I've never been a mixer, I don't want to do anything like that…I usually just say 'well you're not going to change at 83 are you?' you just have to accept that, if that's how somebody feels."* (Nurse 1, focus group)

Personal background

Levels of education, previous occupations and personal or medical history were also considered as issues influencing acceptance or rejection of interventions. The Alzheimer's Society manager questioned whether those with a higher levels of formal education or those whose working lives had involved speaking publicly (such as teachers or academics) were more likely to engage with talking based, group interventions. The following quote reflects this view:

> *"…when you look back into them and you talk to them, I was this person in this office and we used to do x,y and z. You can see why they are very good at being able to come into a group and feel confident enough to speak."* (Manager, Alzheimer's Society)

Also, after the focus group had finished, one of the nurses remained to chat with me. They told me that sometimes when they explained what attending a CST group may involve (such as singing, quizzes and games) to people with a high level of formal education, these people responded in a way that suggested to this nurse that they thought CST might be 'beneath them'. The same nurse also said that they found some other people with dementia, who had less formal education, had said things like, 'I've never really been to school, I don't want to sit in a group'.

Impact of Co-morbidities

All staff recognised that ill health could lead to rejection of interventions. They talked about co-existing acute or long term health conditions, sensory or mobility impairments that some people with early dementia or family members coped with. Within the cohort of people with dementia over the age of 65, ill health, hospital appointments and admissions were a feature of life that staff expected. Staff in the focus group, the doctor and psychologist suggested some of people could find the thought of attending interventions too effortful.

During the focus group the support worker highlighted how physical health problems could prohibit uptake of the CST groups she ran. In the following quote, they explain how they invite people to participate:

> *"...phone call, explaining all what the group's about...it's their choice whether they want to come and attend...nine times out of ten, I don't think we've ever had anybody…we've had people not attending a lot of the reasons is for physical health"* (Support worker, focus group)

The psychologist also reflected that physical health issues could impact on uptake of and engagement with interventions because physical health needs were experienced as more important, as they explained:

"... there's other physical health stuff that for other people top trumps the psychosocial or the mental health stuff. So the moment there's a bit of illness or there's a conflicting appointment at the [names a place] hospital that will always be prioritised over this. And we see that all the time, so then you get the cancellations and the breaks so you don't make the therapeutic gains that you wanted as well" (Psychologist)

The Alzheimer's Society manager reported their service could not offer support for people with particular needs that could be related to age related disabilities or co-morbidities such as assistance with transfers, mobility or toileting. They acknowledged this may consequently restrict uptake of interventions by such people if they did not have the support from others, to assist them to attend.

Not offering interventions due to individual characteristics

I asked the focus group if there were situations when they would not offer psychosocial interventions and why. In response they discussed how they considered the severity of a person's dementia before offering CST, given this intervention was the focus of the discussion. This was because to their knowledge, CST was only recommended for people with mild to moderate dementia. These staff described how some people within the mild to moderate range may struggle to engage with the activities within a CST group, as illustrated by the following quote:

"...the severity, of obviously you...the mild to moderate because you've got to be able to take on board the activities that you're doing, haven't they..." (Nurse 3, focus group)

Also the focus group agreed there were some situations in which individual, complex needs may indicate it was not the right time to offer CST. One nurse gave examples of when people with early dementia and families were struggling to cope with significant longstanding mental health difficulties such as hallucinations, depression and anxiety or alcohol dependency. This person felt, and the group agreed, that management of such issues would take priority over offering CST and such needs may also indicate the person would be unable to manage the activities involved in CST and thus would be unlikely to benefit at that time. These staff agreed they would try to address such complex needs first. This could involve reviewing medications or referring to other services such as community mental health teams, social services or crisis response, for example.

5.6.3 Subtheme: the pivotal influence of family members

All staff highlighted the essential role family members often had in facilitating people with dementia take up interventions. The focus group, psychologist, manager, occupational

therapist interviewed individually and the Alzheimer's society staff all described family members supporting people with dementia. This support was described as involving providing physical care if needed, driving and accompanying people with dementia to interventions or participating jointly in interventions offered to both people, such as CST groups, memory cafes, or cognitive rehabilitation. Their descriptions also indicated a person could be mildly affected by dementia yet have other needs such as assistance with travel, mobility or personal care. Emotional support family members offered also seemed to be viewed as important. The focus group and memory services manager discussed how they suggested family members accompany the person with dementia to the CST groups as that seemed to offer reassurance through a familiar presence. These staff also explained that family members were invited to attend the CST groups to gain information and experience of cognitive stimulation and ideas for carrying out activities at home. The memory services manager suggested that in their experience, often family members encouraged a person with dementia to try CST, when initially the person with dementia themselves was not keen. The following quote illustrates this experience, as well as how the CST groups may be perceived by family members and people with dementia:

> *"Often it's more the families who are pushing for it rather than the client themselves you know because if it's you know a daughter or somebody's whose fetched their mum or dad they often say 'oh I think that would be really good...you know yeah you ought to go for that it'll do you the world of good you never get out you never do anything'. So they look at it more, a bit of a social thing rather than anything, thinking it'll help the person as far as that. But often people say 'oh no I'm not one for group I'm not one for doing that'.* (Manager, memory services)

Some staff discussed how family members could sometimes decline interventions on behalf of people with dementia. The support worker from the Alzheimer's Society considered this may be because family members themselves maybe struggling to cope or adjust. Also, if interventions such as cognitive rehabilitation required tasks to be practised in between sessions, the psychologist said that in their experience this was sometimes perceived as too much by some family members. Some focus group staff wondered if sometimes family members thought CST 'worth it' for two hours given the effort and potential stress of escorting the person with dementia to the venue or arranging transport, particularly if the person with dementia was not keen or co-morbidities made such arrangements feel a burden. The following exchange illustrates these concerns:

> Nurse 1 : *"...but like you say, it's only, we used to do a full day, well people would come all day, have their lunch, whereas you're willing to make the effort for a full day, whereas I think maybe for you know for two hours, they think 'there's a lot of messing about just for two hours really'...especially if they've got mobility problems, or it might be that their wife's coming with them and their wife's got mobility problems...you know the patient might want to go but the relative...it might be that the husband or wife can't*

*get there you know...[*group murmurs*: yeah yeah] ...you know, they want to come together so…*

Occupational Therapist 1: *continence is up there...* [others saying: *yeah yeah, continence, the fear..*]: *you know fear of, being in group situations...needing the toilet*

Support worker: *it's the first thing we do though, when we're in the group, is show people where the toilets are...*

Occupational therapist 1: *yeah cos that can really be anxiety provoking, they can think well I'm not going to go to somewhere new, I won't know where the toilet is, sometimes it's reassuring someone there's a toilet on the same floor can be the difference sometimes*

Manager: *their mobility as well, if they're in a wheelchair, before when we provided transport, that weren't a problem, whereas now, if they want to get here it is…"*
(Focus group)

When the focus group discussed how transport had been previously provided for a day care service, they reported families had often encouraged a person with dementia to attend alone. They thought this may have been because this provided an element of respite for the family, as well support and activities for the person with dementia independently. This discussion suggested these staff thought that if interventions could meet some needs of family members as well as those of people with dementia, it may facilitate uptake. However, it was unclear if the day service they were talking about may have been aimed at supporting people with more moderate, rather than early dementia.

The following quote illustrates how this support worker considered family members could restrict uptake of interventions by people with dementia, due to their own stress or need to avoid confrontation with the person with dementia, the person with dementia was not keen on accepting interventions or the diagnosis:

> *"…sometimes carers will put up a barrier... not for the wrong reason but because they cannot, they cannot see the wood for the trees... the person* [with dementia] *often is saying 'no there's nothing wrong', so in a way it's easier for the carer I think to withdraw a little bit…I mean obviously they are living 24/7 with the person so they're perhaps having a really difficult time, anything that they discuss with the person is a negative coming back from them…"* (Support worker, Alzheimer's Society)

When discussing how they worked with people with dementia and a family member together, the psychologist expressed the vital importance of family support, as the following quote illustrates:

> *"Yeah I guess there's something about the carer's buy in isn't there to the psychosocial offer, I guess that's how I would put it, that if the carer's not buying into that then it can undermine the whole process anyway, so I've certainly had people who we've done, we've had lovely one to one sessions looking at errorless learning and the task has been that the carer supports that several times a day and it doesn't get done and it's actually more about...their beliefs in the approach...so that can probably make or break some of it definitely. And if the carer's feeling really stressed out as well bringing the*

person to the group just becomes another thing that they have to do when they're already quite exhausted. I think my experience has really just been around the buy in yeah" (Psychologist)

There appeared to be a consensus that family members buying in to the potential benefits of an intervention, perceiving interventions as worth the effort, when perhaps they were feeling stressed or exhausted or struggling themselves was an important factor influencing uptake of interventions by people with dementia.

The Alzheimer's Society support worker also considered the role of wives in particular, supporting husbands with dementia to engage in interventions. They reflected that some wives seemed particularly proactive in seeking support for their husbands, which had facilitated uptake of interventions by these men with dementia. The following quote illustrates this point:

"…we have a lot of gentlemen in the group because wives are very keen on, with being the carers of them, being in the caring role, are quite keen on them coming to groups so I think ….I shouldn't generalise but I think women are generally more the carers aren't they...So they are looking for more, what's out there, so I think that's an issue..." (Support worker, Alzheimer's Society)

People with dementia living alone or without regular support from a family member:
All staff accounts suggested that in the course of their work they mostly saw people with dementia alongside a family member and much less commonly alone. The focus group, the memory service manager, and the doctor all said that people with dementia were invited to have a family member accompany them to appointments. They explained that interviewing a family member was part of the diagnosis assessment process, and that a family member could support and reassure the person with dementia as well enabling information to be shared if the person with dementia had limited recall.

The psychologist and OT interviewed individually both said that the cognitive rehabilitation sessions they offered involved both the person with dementia and a family member, to set goals and practice tasks. I asked the psychologist if they had ever worked with a person with dementia that did not have a family member to support them. The following response indicates how a cognitive rehabilitation intervention may not be offered or considered suitable for someone who did not have family member support, unless a support worker could be provided:

"...if there's work that you're doing with someone that requires... that structural support between sessions then you've lost that haven't you, so it makes it much harder, it definitely would flavour the goal or the purpose of what you were doing...So a lot of what we do in rehab...you need all that repetition and rehearsal, so without that

structure [of] the family member there, that would be very very difficult and that would probably be one of the things if that person was I guess, if cognitively they weren't able at least with some kind of strategies to, to be able to implement what you were doing with them without any carer support, we couldn't offer it probably. Or get a support worker... yeah...that would be the ideal...." (Psychologist)

One nurse in the focus group talked about how those who lived alone may worry about burdening family with driving or escorting them to interventions, and thus decline CST, as the following quote illustrates:

"I was gonna say also people who are living alone and they've got support from sons or daughter sometimes feel a bit of a burden, they don't want to ask and put onto their family so that's sometimes comes into it" (Nurse 2, focus group)

The memory services manager also talked about how accessing CST could be problematic for those who lived alone and who could not travel independently. The manager recalled a former day service having their own drivers. They explained how these drivers had got to know the people with dementia who lived alone. This manager's perspective suggested this offered some reassurance to people with dementia who lived alone and who could find getting ready to leave their home on time for appointments stressful or difficult, as the following quote illustrates:

"Yeah rarely people come on their own…It's such a rare occasion... …when we used to run the day service we had our own drivers. So they'd go to pick somebody up and often they wouldn't be ready so our drivers would help them get ready you know, they'd lock the door, check that everything was okay. Whereas now of course we haven't got our own drivers …" (Manager, memory service)

However, these reflections were based on a former day service which would likely have served those with moderate dementia as well as those with mild or early dementia. So, the manager may not have been considering the needs of people with early dementia soon after diagnosis specifically.

Both the Alzheimer's Society staff expressed concern about how their service could support people with dementia who lived alone, as the following quote illustrates:

"...until earlier this year we had a dementia advisor for people who lived on their own...you would see very key examples of people...sustaining that identity, independence...there was about 50 people I think on [name of staff member]'s *books at any one point yeah...some..of those people were people who'd been newly diagnosed so her skills and expertise in that kind of that going back and you know the conversations and somebody who with that fluctuating insight into their, you know, 'how do I feel today as opposed to how I felt yesterday'. And unfortunately when the member of staff retired we lost the service...that was very key in evidencing that kind of*

support, straight to the person with dementia without that carer's presence..."
(Manager, Alzheimer's Society)

The Alzheimer's Society staff also explained they could offer telephone befriending to those who were isolated, declined other interventions or were unable to attend interventions. The following quote illustrates this as well as some of the complex reasons why people with dementia may not engage with interventions:

> *"She was a really lonely lady, so we provide telephone befriending…So that's something that she did accept, so somebody that I supervise rings her from time to time just to talk, she's grieving and she's got an alcohol problem as well as dementia..."*
> (Support worker, Alzheimer's Society)

The Alzheimer's Society staff had also explained that their service could not offer assistance with physical care needs, mobility or and transfers. This account suggested that people with such needs who did not have another person to support them may be unable to take up intervention offers, as the following quote illustrates:

> *"And we don't provide personal care at services, so somebody has to be, have...either somebody with them to provide that or be able to manage it themselves...using the loo and things like that, we're not in a position to support people you know in and out of a bathroom...there are those restrictions because... we're not in a nursing environment, well we don't want to be... and it can isolate people."* (Manager, Alzheimer's Society)

5.7 Theme 3: Communication and relationships

Theme 3 is about how staff described communicating with people with dementia and families. One subtheme: 'Respecting personal choice and consent' was also identified.

The ways staff described communicating with people with dementia and families to try and encourage uptake included offering reassurance, reoffering interventions to those who decline and building trust. Memory Services 1 staff and the psychologist also talked about sharing their understanding of the evidence base for CST with people with dementia, to encourage uptake.

Offering reassurance

I asked the focus group about how they might encourage people to participate in psychosocial interventions. In response, they talked about trying to encourage uptake of CST. As the subtheme within Theme 2, 'Impacts of dementia on individuals' indicated, these staff acknowledged that people may be struggling to adjust to the diagnosis or experiencing decreased confidence and self-esteem and so reject offers of attending CST. The focus group discussed and identified a number of ways of offering reassurance to those who

seemed nervous or uncertain about attending a CST group, by for example: suggesting bringing a family member with them or just trying one session, with no obligation to return. These staff also talked about how they tried to explain clearly what was involved as it would be an unfamiliar activity that people with dementia and family members may not be able to imagine so gave examples of what sessions involved. The focus group also agreed they tried to introduce people with dementia to group facilitators in person at memory services. The support worker and occupational therapist in the focus group, who ran the CST groups confirmed they tried to meet people if possible (i.e. they were in the building and available) or would always telephone people before a person's initial attendance to try and help people feel at ease and begin building rapport.

The memory services manager considered that sometimes people's experiences of the diagnostic assessment process at memory services had been to feel anxious, distressed or unhappy, perhaps because of being confronted with their declining cognitive skills. This manager wondered if this could discourage acceptance of CST. They described trying to reassure people that attending a CST group would not be like previous visits:

> *"…talking about all this post-diagnosis support, what's available like the CST and everything … I think a lot of them sometimes think… 'oh god is it going to be somebody asking me all these questions every time I come', which is obviously going to be anxiety provoking for the best of people isn't it … I then have to say…it won't be like this it's all really good fun and the people who come we find that they all really enjoy it and never want the 14 weeks to end… often the case once you get people through the door…sometimes that helps as well because I do think people tend to think 'no I'm not coming back here…to do this all again."* (Manager, memory services)

Promoting the evidence base for CST

The manager, some focus group participants and the psychologist, who all worked at Memory Services 1, described how they talked to people with dementia and families about the evidence for CST, as they understood it. These staff said they explain CST is recommended by NICE (National Institute for Health and Care Excellence) and has been found to be as beneficial as some of the medications prescribed. The manager of memory services explained that staff were all trained to explain this as the rationale for offering CST. The following quotes illustrate this approach to communicating with people with dementia to promote uptake of CST whilst offering reassurance:

> *"…I say there's no magic pill…even though for a lot of people they do…stabilise their cognitive function, with the medication but it generally works hand in hand with this intervention* [CST] *that's obviously, NICE approved and.. try to be very clear that they're not you know booked into this 14 week gruelling session whether they like it or not but just see how it…"* (Nurse 3, focus group)

"…when people say 'oh I'm not ready for that, we're not that bad yet', I do try and talk to them about CST...that is where I say research will show that this is as good as the medication we're giving you if not better if practised regular. So you know it is very beneficial, it's only a 14 week programme, and you know that could end up benefitting you for many years. We do invite the carers to come along as well so that the person doesn't have to feel uncomfortable coming on their own. And you know so we try and push it by saying things like that really as well" (Manager, memory services)

"...usually just telling somebody that you know the outcomes of the CST are comparable to donezepil, for example is enough just to swing people. So perhaps it's the way that we sell it…" (Psychologist)

Reoffering interventions

If people with dementia and family members declined CST, the focus group agreed this would be offered again at subsequent review appointments with a nurse or possibly during occupational therapy sessions, if an OT were involved. One of the OTs in the focus group said they worked with people in their own homes. They described how this sometimes facilitated a different type of conversation and response to occur, suggesting this may be because people had the chance to consider the offer of CST and experienced the impact of dementia on their lives a bit more, as the following quote illustrates:

Occupational Therapist:*"...I often go out later when people perhaps have a few more needs...I suppose it's still early stages but then you can actually, then I you know broach the subject again*

[Becky Field (researcher): *and in you're in their home? Is that right?]*

Occupational Therapist: *yeah the dynamics are totally different they've had time to think about it, they've experienced a bit more of what it's like and maybe want to, maybe they are just more ready to do that kind of thing, or not..."* (Focus group)

Building trust

The psychologist talked about how in their view, people with dementia and family members needed to feel they could trust staff offering interventions, in order to accept them. They felt being familiar with memory services and the staff there helped this. They questioned whether a lack of familiarity with memory services could explain why there had been limited uptake of CST by people diagnosed in primary care by GPs in their location. The psychologist said that in contrast, for people who were diagnosed by memory services, staff would have started to build a relationship with people over the course of assessment.

"…the rapport that we've got…if it's a patient that I've known for a while and do quite a big assessment with, at that point they generally trust what we're recommending… for many people their relationship's very important, so have they got a relationship to that service where they feel safe there? Because the unknown is quite daunting isn't it and...I think that's one of the reasons why we have a higher uptake for CST here than in primary care…" (Psychologist)

This perspective contrasted with the view expressed by the memory services manager whose expressed experience was that some people were discouraged from attending interventions at memory services because they had found the process of assessment upsetting. These different perspectives represent the different experiences of these two different members of staff, based on their own experiences.

5.7.1 Subtheme: Respecting personal choice and consent

The importance of gaining consent from people with dementia for referral to interventions, or other support services, was discussed by the focus group and the Alzheimer's Society staff. These staff talked about how they would not refer people to interventions without their consent. They acknowledged that sometimes people needed more time to be ready to accept interventions. The focus group agreed that they would re-offer CST at subsequent contacts. The focus group and the psychologist talked about how people who declined interventions initially may later take up offers, when they had had more time and a chance to consider the diagnosis. When I asked focus group participants what they might do when a person with dementia clearly rejected an offer of CST, the responses were as follows:

> Nurse 1: "*nothing!*
>
> Occupational Therapist 1: *nothing, it's their choice*
>
> Nurse 2: *well they take the leaflet away in the pack so you might revisit it later....*
>
> Nurse 3: *we'd probably raise it again there, we do have uptake it's not always just at PDS* [the first post-diagnostic support appointment] *is it? After one or two reviews if they're staying quite stable they might take it up…*
>
> Support worker:…*when they are doing a group we say they can stop doing it any time, they can stop attending, it's their choice, whether they want to come or not"*
> (Focus group)

The Alzheimer's Society staff explained that if people with dementia declined their service then offering interventions was not possible. However, these staff explained they could work directly with a family member directly, if this person wanted their service, to meet their individual needs without working with the person with dementia directly. The following exchange highlights this approach and how these staff hoped by supporting the family member the person with dementia was indirectly supported:

> Manager, Alzheimer's Society: *"…we come away from the... initial contact and kind of you can put your head in your hands and think there's so much we could actually offer here but the person said no and if the person doesn't give us consent there's nothing*

we can do about that...it might be then that the wife gets in touch and says actually I really need the help and that...

Support worker, Alzheimer's Society: ..w*e end up supporting the carer probably*

Manager: *and not predominantly the person with diagnosis*

Support worker: *I think, by supporting the carer we are supporting*

Manager: *In a sense yes, I always look at it as an ongoing...."*

These staff also explained said that if a person with dementia refused contact with the Alzheimer's Society, this would not prevent future contact, people could always change their minds, contact the service in future or re-referral from professionals would be accepted. The focus group did not talk about working with family members directly. The memory services manager, psychologist and occupational therapist interviewed individually discussed carers support groups but not working with a family member alone if a person with dementia had declined support from memory services.

5.8 Theme 4: Unmet needs and ideas for service developments

Overall there was limited discussion about unmet needs and ideas for service developments. I did not ask questions about these topics of the focus group, memory services manager and occupational therapist interviewed individually due to limited time. Most staff did not discuss alternatives to the interventions currently offered within their settings. However, some staff did discuss the following ideas:

Interventions to address needs for emotional support and individual needs

The psychologist talked about wanting to offer, if time and resources could be made available, more choice of interventions to meet individual needs and needs for emotional support and adjustment, as explained in the following quote:

> *"…we want the cognitive rehab to be a proper part of the pathway, where there's clear indicators about who we offer to and who we don't and whether it's indicated for group or individual work. We would want a kind of post-diagnostic adjustment group for people who are struggling to adjust to the diagnosis…we're wanting to be able to trial something called the 'STaRT[2] Intervention… it's [got]…good cost effectiveness ... good evidence base…so it's a lovely, really easy to deliver intervention. But being given the resources to deliver that is … there's quite a good evidence base now for adjustment groups…talking as a group and just gradually trying to facilitate the assimilation of the dementia into that person's self in a non-threatening way"*
> (Psychologist)

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[2] STaRT stands for 'STrAtegies for RelaTives': an eight week intervention for carers aiming to reduce anxiety and depression in carers and improve coping (195)

The doctor did not identify unmet needs or changes, saying:

> *"So it's quite a tricky one, how would I change things? I'm not sure I would..."* (Doctor)

The doctor reiterated their view that they, as a medical professional, needed to prioritise what they discussed, for example, assessment results, diagnosis and medication, within the limited time they had with people, although they would try and briefly discuss the information pack or education and information sessions if time allowed.

Interventions to support people who demonstrate limited self-awareness to others

The Alzheimer's Society support worker reflected on the need to support people with early dementia who may not demonstrate self-awareness to others but could still potentially benefit from engaging in enjoyable activities. Other staff had also described people with limited self-awareness or those who did not acknowledge the diagnosis, rejecting interventions, but had not talked how such issues might be addressed, perhaps indicating limited views of the range of possibilities for addressing such issues. The following quote illustrates the challenge this support worker had in trying to consider what alternative interventions may be suitable:

> *"…if people are affected and they don't have that insight... what is there for those people really? They miss out there must be something else other than you know, it's a talking group...They miss out…It's easier to engage with people if they are going to engage with us.... ...It is very very hard isn't it?… if someone's… 'there's nothing wrong with me I'm fine'…it would be nice I suppose if we could have offered more groups perhaps to people who haven't got the insight and think about ways of perhaps involving them in a group…different route. Whether you could bring images or…(tails off)"* (Support worker, Alzheimer's Society)

Support to access interventions, particularly for those without regular support or co-morbidities

All staff expressed concern that limited or lack of transport provision and difficulty travelling independently affected uptake of interventions by people with dementia. Some staff in the focus group, the doctor and memory services manager discussed that even those people with family support may be discouraged from attending interventions, if they felt this could burden their families or family members may be unable to drive them due to working or ill health. These staff suggested that providing transport may increase uptake of interventions.

Whether there was a need for people with dementia without family support to have someone familiar accompany them to interventions, to support and encourage them, which could facilitate uptake, was mentioned by this support worker:

> *"I just think, people on their own as well they need to be accompanied by somebody that they trust, somebody familiar so it's that."* (Support worker, Alzheimer's Society)

Both the occupational therapist interviewed individually and the memory services manager had talked about how people with dementia rarely came to memory services alone. The following quote illustrates how this memory service did try to provide transport to people who had no alternative:

> *"Yeah rarely people come on their own ...It's such a rare occasion, you know on rare occasions we have like paid for transport....if there is anybody who was to live on their own there have been occasions where we do provide the transport but it's not really that we encourage we do do it."* (Manager, memory services)

Seeking the views of local people with early dementia about the kinds of services they need

The manager from the Alzheimer's Society talked about the need to consult with and seek the views of local people with early dementia over 65 years old directly about what kinds of services and interventions they considered that they needed, to inform local service development. They talked about how this had been done with people with dementia under 65 years old in their locality and with carers, when I asked if they thought this should also be done with people older than 65 affected by dementia, they replied:

> *"Yeah absolutely, I think it's about creating...what people want and we do a lot of stuff at the moment around the service user, the kind of voice, the voice of service users and they're kind of, what is it, what can we do to make things better. The consultation group for carers that happened in July...so we're always trying to listen to what people are saying in the sense of the types of things that they need, it's often about the facilitation of and how can we do it"* (Manager, Alzheimer's Society)

Culturally appropriate interventions

The manager from the Alzheimer's Society also questioned whether the interventions currently available met the needs of specific communities. Whilst they thought that current services were open to and offered to all, they acknowledged uptake by certain groups was, in practice, limited. They wanted services to develop specific interventions to meet the needs of people with dementia from minority ethnic communities and lesbian, gay, bisexual and transgender people (LGBTQ+) with dementia. The following quote highlights this view:

> *"…I think* [location 2] *has 100 speaking languages…so there are things that we can do to make it more open. We're only just touching stuff around like the LGBT community… People say what would you do if somebody had…grown into their 50s… came out as a gay woman…prior to that had been married to a man and now the dementia had regressed to the memory …we were in…GP practices for six months…looking at how we could position ourselves within certain cultural groups and say you know, dementia will affect you at some point, within your cultural group somebody will be affected by dementia because it doesn't discriminate and people saying we don't know what that is, there isn't a word in our language for dementia…"* (Alzheimer's Society manager)

Chapter Summary

Chapter 5 has presented the findings from interviews conducted with staff. A convenience sample of 12 staff was obtained. One focus group was held with staff working at the same memory service and semi-structured interviews were conducted in person or by telephone with other staff. Four key themes identified influences on acceptance and rejection of interventions by people with early dementia, from the perspective of these staff. Theme 1 was about the influence of service contexts and wider society. Theme 2 was about individual characteristics of people with dementia and family members. Theme 3 was about the importance of communication and relationships between staff and people with dementia and families. Theme 4 identified some unmet needs and suggestions for service developments.

Next, Chapter 6 brings together the findings from thematic analysis and triangulation to present overall findings from all interviews completed for this research i.e. solo interviews with people with early dementia, joint interviews with people with dementia and family members and interviews with staff, to present overarching themes.

Chapter 6 Triangulation of findings and overarching themes

This chapter presents findings from triangulating key themes and subthemes previously identified from the solo interviews completed with people with dementia, those held jointly with people with dementia and family members and the focus group and interviews held with staff (presented in Chapters 4 and 5). Triangulating findings from these different types of participants and different methods of data collection aimed to identify similarities and differences about influences, from these different perspectives, on acceptance or rejection of interventions by people with early dementia. These triangulated findings are presented as five overarching themes.

6.1 Findings from triangulating the different interviews

Similarities and areas of difference between findings from the thematic analysis completed for the solo and joint interviews with people with dementia and family members and the thematic analysis of staff interviews and the focus group were identified using triangulation. The methods used to carry out triangulation are presented in Chapter 3 (Section 3.9.2) and involved assessing the two different sets of interviews for 'convergence' (158).

Overall, I identified five key themes and eight subthemes from the solo and joint interviews with people with dementia and family members. I also identified four key themes and seven subthemes from the staff interviews and focus group. This resulted in an overall total of nine key themes and 15 subthemes. To triangulate findings, each transcript was examined to identify whether topics connected to each of the nine key themes and 15 subthemes could be identified. I used a triangulation matrix (158) to assess the convergence of themes and subthemes across all the transcripts, organise and summarise findings. Table 6.1 provides a summary of the triangulation matrix to illustrate the areas of convergence and difference between the different themes and subthemes identified.

Table 6.1.Summary of the triangulation matrix used for convergence assessment

THEME	Convergence code	Summary of topics connected to themes and subthemes		Number of transcripts with topics connected to theme or subtheme	
Key themes and subthemes from solo and joint interviews with people with dementia and family members		Solo and joint interviews with people with dementia and family members	Staff interviews and focus group	People with dementia & family members (n=16)	Staff (n=7)
1. **Adjusting to life after diagnosis**	Agreement	The diagnostic process, adjusting to diagnosis and coping were discussed, leading to identification of this theme.	Different responses to diagnosis, coping and adjustment were discussed; accounts indicated that how people were adjusting to life after diagnosis affected responses to intervention offers.	15 (94%)	6 (86%)
Subtheme 1.1 Self-awareness & differing accounts of dementia	Agreement	Awareness of dementia and its impact. Some noticed significant impacts of dementia, others felt impact of dementia to be currently minimal or that it was 'early days'. Some accounts illustrated different understandings of dementia held by the person with diagnosis compared to family members or staff. These issues led to the identification of this subtheme.	Most staff accounts discussed challenges of engaging people who may not acknowledge their diagnosis, demonstrate limited self-awareness or who do not report experiencing significant problems.	15 (94%)	6 (86%)
2. **Appeal of interventions & perception of benefit**	Partial agreement	Personal interests, valued activities and whether or not interventions were regarded as potentially beneficial were discussed. These issues appeared to influence how people with dementia and family members responded to intervention offers, leading to identification of this theme.	Staff did not discuss how people with dementia's personal interests or hobbies may influence response to intervention offers. Some did discuss whether people with dementia and families considered if interventions would benefit them or not. Some also talked about how some people with dementia reporting they were busy or active socially and thus may not perceive a need for intervention.	16 (100%)	3 (50%)

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THEME	Convergence code	Summary of topics connected to themes and subthemes		Number of transcripts with topics connected to theme or subtheme	
Subtheme 2.1 Personality & personal narratives	Agreement	Personal interests, occupational backgrounds, life stories and interventions engaged in or declined were discussed; interventions 'fitting' a person's narrative, or not, appeared connected to acceptance or rejection of interventions, leading to the identification of this subtheme.	Staff talked about the personalities of people with dementia and people with dementia people describing themselves as liking or disliking groups. Educational or occupational background, were also identified by some staff as potentially influencing uptake.	12 (75%)	6 (86%)
Subtheme 2.3 Mixing with others with dementia	Agreement	Some people with dementia and family members appeared anxious or fearful about meeting others with dementia who may be more severely affected than themselves, leading to identification of this theme.	Some staff talked about how they thought some people with dementia they had worked had been nervous or fearful of meeting others with dementia or were not ready to do this, as they were still adjusting to their diagnosis. These issues were felt to discourage uptake of interventions, in these staff's experience.	5 (31%)	4 (67%)
3. **The service context**	Agreement	How interventions or services had been offered, where i.e. in what context were discussed, leading to identification of this theme.	All staff accounts discussed where intervention offers were made, where interventions were provided, and at what points in the post-diagnostic pathway interventions were offered by the different services they worked in.	16 (100%)	7 (100%)
Subtheme 3.1 Signposting & information provision	Partial agreement	Some people with dementia and family members discussed their experiences of, and views about, information packs or being signposted to other services, leading to identification of this subtheme.	Staff working in memory services discussed information packs and most staff discussed signposting people with dementia and families to other support services.	9 (56%)	7 (100%)
Subtheme 3.2 Practicalities: travel, locations, venues	Agreement	Location, venues and transport were talked about as key influences on uptake leading to the identification of this theme.	Nearly all staff accounts discussed how travel, location and venues could impact on uptake. , Some staff expressed concern about how those without family support could access interventions, or how those with family support could worry about burdening family, distances within service catchment areas, poor public transport and potential stress of journeys were perceived to discourage uptake.	13 (81%)	6 (86%)

THEME	Convergence code	Summary of topics connected to themes and subthemes		Number of transcripts with topics connected to theme or subtheme	
Relationships	Agreement	Some family members talked about how they had encouraged the person with dementia to attend interventions when they were uncertain about doing so. Family members also provided support by driving people with dementia to interventions, attending interventions and appointments with them, promoting and reminding, assisting with personal care or mobility if needed Also, some talked about how particular staff helped them feel comfortable or listened to, or not. These issues appeared to influence uptake of interventions, leading to the identification of this theme.	Some staff talked about how family members supported people with dementia by encouraging them to try interventions, by driving and accompanying them. Some staff also talked about how they to offer reassurance and encouragement.	16 (100%)	3 (43%)
Subtheme 4.1 Persuasion & encouragement	Agreement	Some family members talked about how they supported, persuaded or encouraged people with dementia to take up interventions, when intervention offers had initially been rejected or the person with dementia did not seem keen, leading to identification of this subtheme.	How people with dementia could be encouraged to try an intervention, either by family members and by staff themselves was discussed by some staff.	5 (31%)	3 (43%)
Subtheme 4.2 Managing fear & anxiety	Agreement	Some people with dementia and family members talked about fear of the future and anxieties about attending services, and how they coped with such feelings. Such feelings appeared to influence uptake of interventions leading to the identification of this subtheme.	Topics connected to fear and anxiety were identified in some staff accounts, and perceived as influences on uptake. Some staff discussed how they tried to reassure people when offering interventions, to encourage uptake.	8 (50%)	3 (43%)

THEME	Convergence code	Summary of topics connected to themes and subthemes		Number of transcripts with topics connected to theme or subtheme	
4. **Unmet need and suggestions for services**	Partial agreement	Many people with dementia and family members said they did not want or need more or different support from services. It seemed they felt their needs were met by family or by current interventions. Some said they would like to continue to attend groups they had already participated in. Suggestions made focused on support to manage emotional responses to diagnosis and work. Most people with dementia seemed keen to pursue community based activities as they always had and non-dementia specific activities such as day trips and visits but some needed support to do so. A few family members talked about lack of contact or support for particular diagnoses. When asked about potential participation in physical exercise interventions most responded they would be keen if they felt physically able. These issues led to the identification of this theme.	Unmet needs and suggestions were made by some staff only and were different to those identified by people with dementia and family members. However, such discussions, in common with those raised by people with dementia and family members, implied that more and different types of intervention to meet individual needs were required, and the need to offer support with adjustment and managing emotions after diagnosis was identified by the psychologist.	13 (81%)	3 (43%)
Subtheme 5.1 Living well with dementia	Silence	People with dementia and family members were asked how they might advise others to live well with dementia. Some said, for example: 'carry on', 'ask for help', 'mix with other people', leading to the identification of this theme.	Topics connected with this theme were not identified. Staff were not asked a similar question.	11 (69%)	-

THEME	Convergence code	Summary of topics connected to themes and subthemes		Number of transcripts with topics connected to theme or subtheme	
Key themes and subthemes from interviews and focus group with staff					
A. Context: service contexts and wider society	Agreement	Topics connected to the context of service delivery such as types of intervention people with dementia had attended or declined, where and when were discussed.	Context of service delivery (e.g. types of intervention offered, when and where) was described by all staff. Some staff talked about stigma discouraging uptake. Resource management and its impact on interventions and services were discussed. These issues led to identification of this theme.	16 (100%)	7 (100%)
Subtheme A.1 Different types of intervention to encourage engagement with services	Partial Agreement	Different types of intervention were discussed; participants talked about interventions offered, taken part in or declined. But, these interventions were not described as a way in which services might encourage acceptance of intervention. These participants described less types of intervention than staff described as offered to people with dementia in their locations.	Staff described different types of intervention This appeared to be one way services tried to encourage engagement. For example, information packs or signposting, information/education sessions or drop-in sessions or more structured interventions such as CST or peer support requiring regular attendance. A greater range of interventions were reported by staff than by participants with dementia or family members. These issues led to the identification of this subtheme.	15 (94%)	7 (100%)
Subtheme A.2 Accessing interventions and practicalities	Agreement	People with dementia and family members talked about how they travelled to interventions; location, venues and transport were all talked about, and identified as key influences on uptake. Most of the people with dementia appeared reliant on family members to help them access interventions, although some were able to travel independently and did attend interventions alone.	How people with dementia and families could access interventions, travel, location and venues were discussed. Some staff expressed concern about how those without family support could access interventions or if family members were unable to travel easily. Some staff also talked about how some people with dementia who had family support worried about burdening family. These issues and distances within service catchment areas, poor public transport and the potential stress of	14 (88%)	6 (86%)

THEME	Convergence code	Summary of topics connected to themes and subthemes		Number of transcripts with topics connected to theme or subtheme	
			journeys creating anxiety were perceived to discourage uptake. These issues lead to the identification of this subtheme.		
Subtheme A.3 Societal influences	Partial agreement	Some accounts indicated that people with dementia or family members felt the effect of stigma associated with dementia. It appeared this may have affected acceptance or rejection of intervention offers. No accounts talked explicitly about the impact of media coverage of dementia on them or stigma felt.	Media coverage of dementia affecting uptake was discussed by one staff participant. Stigma associated with dementia was discussed across several interviews, as discouraging uptake. Identifying both these topics led to the identification of this subtheme.	12 (75%)	5(71%)
B. Individual characteristics as influences on uptake	Agreement	Personal interests, how people with dementia and family members liked to spend their time now and in the past, previous occupations, were much discussed. Also several people with dementia and family members talked about how dementia was affecting their daily lives.	Staff accounts discussed individual characteristics such as personality traits, for example not wanting to participate in group activities, occupational background or characteristics such as severity of dementia or other medical conditions affecting responses to interventions. These issues led to the identification of this theme.	14 (88%)	6 (86%)
Subtheme B.1 Impacts of dementia	Agreement	Severity of dementia, memory loss, behaviour or mood changes were discussed. Accounts from people with dementia and family members indicated that such impacts had influenced responses to intervention.	Severity of dementia or people with dementia and families feeling the impact of dementia on them to be minimal, and how people were adjusting to diagnosis were suggested as possible reasons for acceptance or rejection of intervention, leading to the identification of this subtheme.	14 (88%)	6 (86%)
Subtheme B.2 Personality and background	Agreement	Personal interests, enjoyment of socialising, occupational and leisure histories were discussed. These factors appeared to influence people's uptake of interventions.	Some staff talked about how some people with dementia described themselves as never having liked groups. Some also talked about whether occupational histories or educational level potentially influenced uptake, leading to the identification of this subtheme.	14 (88%)	6 (86%)

THEME	Convergence code	Summary of topics connected to themes and subthemes		Number of transcripts with topics connected to theme or subtheme	
Subtheme B.3 Pivotal influence of family	Agreement	Joint interviews demonstrated the influence of the family member on the person with dementia, through the practical and emotional support provided to the person with dementia in daily life as well to attend interventions and acceptance of interventions. People with dementia interviewed alone and some joint interview accounts talked about how family who were not interviewed influenced their decisions to engage in services.	Staff accounts indicated concern about how people with dementia without family support could engage with interventions. Staff suggested some people with early dementia may be unable to travel independently and also that family members may encourage acceptance of interventions when a person with dementia was not keen initially, offering reassurance and attending with them These issues led to the identification of this subtheme.	16 (100%)	6 (86%)
C. Communication and relationships	Agreement	Some people with dementia and family members talked about how staff communicated with them, both positive and negative accounts were given about the way staff had communicated. This seemed to influence responses to intervention and service offers. The relationships people with dementia had with family members, and how family members communicated with people dementia, to encourage or support them to engage in interventions also appeared important.	Staff accounts discussed how they tried to engage people with dementia and their families when offering interventions. Staff talked about the kinds of things they said say to encourage uptake. These issues led to the identification of this theme.	11 (69%)	6 (86%)
Subtheme C.1 Respecting choice and consent	Partial agreement	Some family members talked about how they responded if people with dementia were not keen to attend interventions. These family members alluded to feeling they needed to lead or make choices for the person with dementia about: attending interventions. This was because the person themselves might	Some staff discussed how they respected the personal choice of people with early dementia to decline interventions, and regarded this as necessary and important to do. Referring people with early dementia to other services only with their consent was also regarded as important. These issues led to the identification of this subtheme.	4 (25%)	2 (29%)

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THEME	Convergence code	Summary of topics connected to themes and subthemes		Number of transcripts with topics connected to theme or subtheme	
		not wish to, or feel uncertain but the family member believed it was important to try to see if the person with dementia enjoyed the intervention once there or the family member felt pretty certain that the person with dementia would enjoy participating, based on their knowledge of the person.			
D. Unmet needs & ideas for service development	Partial agreement	Many people with dementia and family members seemed to feel their needs were currently met by family or services. Some said they would like groups they had already participated in to carry on. Suggestions made focused on support to manage emotional responses to diagnosis and work related roles, Interest in pursuing non-dementia specific activities such as visits to places of interest was also expressed. Some family members expressed concern about the need for monitoring or or advice for people with particular diagnoses. When asked about whether they would like to participate in physical exercise most responded they would be keen to do this if they were physically able.	A few staff accounts identified areas of unmet need and suggestions for service development. These implied a need for more different types of intervention. For example: groups to support emotional adjustment post-diagnosis, interventions for people with limited self-awareness, culturally and LGBTQ+ appropriate interventions. Consulting local people with early dementia about what support they would like was also suggested. Support to access interventions e.g. transport provision, particularly for those who do not have family support was also discussed by some staff who thought if transport were provided, uptake may increase. These issues led to the identification of this theme.	13 81%	3 (43%)

NB: percentages rounded up; one staff interview was the initial interview conducted with the manager of Memory Services 1 prior to all other data collection. This interview focused on contextual information about the service, staff team and potential recruitment strategies, rather than this participant's perspective on reasons why people with dementia and family members may reject or accept intervention, although these were obtained in a second interview.

To summarise, for six (of nine) key themes, topics connected to the themes and subthemes were found in transcripts from each set of interviews (i.e. solo and joint interviews with people with dementia and interviews and the focus group with staff), resulting in an 'agreement' rating for convergence. For three key themes, some notable differences between how or how much the topics had been discussed, between the interviews with people with dementia and family members, and staff, were identified. This resulted in a rating of 'partial agreement' for convergence. For nine of the 15 subthemes, references connected to these subthemes were found in transcripts from staff interviews and the focus group and those from interviews with people with dementia and family members so ratings of 'agreement' were given. For five subthemes, some notable differences about how the topics discussed were found, between the interviews with people with dementia and family members, and the staff interviews, resulting in ratings of 'partial agreement'. I identified one area of silence when examining the transcripts. This was for *'living well with dementia',* a subtheme identified from the interviews with people with dementia and family members. Staff had not been asked for their views about what might contribute to living well with dementia, therefore this was given a rating of 'silence' for convergence as this topic was not referred to within the staff interviews and focus group.

Overall, when completing this triangulation exercise, I did not identify any major areas of divergence and identified many areas of convergence between the findings from interviews completed with people with dementia and family members and interviews completed with staff. Thus triangulation enabled me to identify five overarching themes. To identify these overarching themes I privileged the accounts from people with dementia and family members. This was because I used the themes and subthemes identified from those interviews as a starting point, and then considered whether and how staff accounts agreed with or diverged from these. Of course the topics identified in transcripts from interviews with staff which related to the themes identified from the solo or joint interviews with people with dementia, came from the perspective of each type of participant and thus were different. However topics raised in each set of interviews were also connected. The five overarching themes are now presented.

6.2 Overarching themes

The five overarching themes are:

1. Adjusting and awareness

2. Intervention appeal and perceived benefit

3. Context of services and stigma

4. Relationships and communication

5. Unmet needs and suggestions for services

6.2.1 Overarching theme 1: Adjusting and awareness

People with dementia and their family members described still coming to terms with the diagnosis. Feelings of shock and fear, and distress were expressed by some. These feelings were related to anxiety or fear for the future, yet such perspectives mostly seemed encourage uptake for some of these participants. Staff accounts also consistently acknowledged that how people with dementia and families were adjusting to diagnosis and coping with their everyday lives influenced responses to interventions. Several staff discussed how in their experience, some people with early dementia were still getting used to the diagnosis, struggling to adjust and thus declined interventions.

During interviews, some people with dementia openly acknowledged the diagnosis and demonstrated awareness of changes they were experiencing due to dementia. They described memory loss, low mood and frustration. Most of these people seemed keen to attend interventions, given these challenges. They wanted support, either from professionals or peers, or both, and most wanted to socialise with others as they felt social interaction to be important to maintain their functioning and enjoyed it. However, there were also some people with dementia who gave different accounts or understanding of their experience of dementia compared to family members or staff. Most staff accounts similarly indicated the importance of awareness of difficulties; that having an awareness of difficulties, as well being able to accept the diagnosis, may encourage acceptance of interventions. Several staff talked about people with dementia having 'insight' or not. Some staff described working with some people who did not believe themselves to have dementia or described that the effects of dementia on themselves as minimal or and manageable. These staff felt these people were likely to reject interventions as they did not perceive a need for such support.

Adjusting to a diagnosis and readiness to try an intervention appeared to be a process. Most staff talked about the importance of re-offering interventions at subsequent meetings with people who may have rejected offers previously. These staff recognised that people may come to acknowledge the diagnosis or the impact of dementia on their lives as they lived with dementia over time. Some participants with dementia who in interview appeared reticent about participating in interventions were also able to reflect on this and seemed willing to try an intervention, if they thought it may benefit them or their family members. Whether

interventions were perceived as beneficial and whether they appealed to people with dementia are discussed next, in overarching Theme 2.

6.2.2   Overarching Theme 2: Intervention appeal and perceived benefit

Some people with dementia talked about being keen to try interventions they had been offered. Others were uncertain about whether interventions appealed to them or held potential benefit for them as individuals. Some people with dementia and family members regarded interventions as offering opportunities to socialise and for peer support, which were valued. Other specific activities involved in interventions also appealed to some, such as singing, dancing or playing games, as well as socialising. Some people with dementia talked about valuing mental stimulation. These people recognised mental stimulation as beneficial given their diagnosis of dementia. Some people with dementia said that new activities or group interventions would be worth trying and some described themselves as the 'type' of person who had always joined in with things. Many talked about their personal interests and pastimes over the years. Most people with dementia described being active in retirement, volunteering in some capacity or being involved with local organisations, such as churches or a pensioner's club. It seemed deciding to participate in a group intervention was something they found acceptable and that the interventions they had engaged with had 'fitted' their interests and personal narrative. Whilst staff did not talk about people's individual interests or histories as the participants with dementia themselves did, several staff did discuss how personality and feelings about group interventions was an important influence on responses to group interventions. Two staff questioned whether educational level, a professional background or work experience may lead some people with dementia to feel more comfortable in group settings and more likely to accept group interventions, than those without such backgrounds, perhaps not so used to or comfortable interacting with groups of unfamiliar people.

When interventions did not appeal or potential benefits were not perceived

Some other people with dementia and family members did not appear convinced that interventions would benefit them. For example, several participants with dementia talked explicitly about how attending groups did not appeal to them, although all but one of these participants had in fact attended a group intervention, or planned to, despite reservations. It appeared this had happened because they had been encouraged to attend by their family members. The way family and staff encouraged uptake is discussed in Overarching Theme 4: 'Relationships and communication'. Various reasons were given for reservations about the potential value of group interventions by people with dementia. Some questioned whether a CST group may be too formal or when asked whether they would like to participate in quiz

like activities a few expressed concern it may be too demanding given their reduced cognitive abilities. These participants appeared to lack self-confidence. Some people with dementia and family members expressed concern about meeting other people with dementia, perhaps those more severely affected than themselves and this discouraged them from attending interventions. Some people with dementia and family members also talked about being busy, for example caring for grandchildren, having active social lives, or with jobs at home. These issues appeared to discourage uptake. Staff accounts acknowledged these issues too. For example, focus group participants agreed that some people with dementia appeared to feel busy, coping with life independently and connected socially. These staff considered that some people tended to regard CST groups as primarily offering social interaction and so some would perceive little benefit in attending. Several staff acknowledged that people with dementia and families can feel fearful or anxious about mixing with other people with dementia, particularly if they were struggling to adjust to the diagnosis, and this could discourage uptake of group interventions, such as CST. A few people with dementia and family members reported negative past experiences of services. These experiences seemed to colour negative responses to subsequent intervention offers from memory services from those participants who reported these experiences, at least initially. One member of staff talked about the experience of being 'tested' at memory services perhaps discouraging uptake of CST offered by memory services. They suggested the diagnostic process confronted people with their changed cognitive abilities and so some people thought attending a CST group may involve similar activities. Although it is also important to note another staff participant also expressed the view that the diagnostic and testing process could help build trust and rapport and this sometimes facilitated uptake, in their view. Staff also agreed that some people simply were not 'group people' and may never have been.

Different types of intervention

Staff described how services offered different kinds of interventions. Memory services staff talked about providing an information pack initially and then offering more structured groups such as CST or an education and information group requiring regular attendance. Alzheimer's Society staff talked about offering tailored support via home visits or telephone to identify what kind of support, if any, people with dementia and families wanted. They explained that then would they make suggestions for other interventions, whether provided by the Alzheimer's Society, the NHS or other community organisations. Memory services staff did not discuss non-dementia specific interventions or activities. Alzheimer's Society staff reported working with community based, non-dementia specific organisations to support them to develop activities suitable for people with dementia. People with dementia and

family members described participating in different interventions, such as CST, an education and information group, a life story group, an exercise group memory cafes and 'Singing for the Brain'.

Groups as the main mode of intervention delivery

All interviews indicated that group interventions were the main mode of delivery for interventions offered. Nearly all of the interventions people with dementia and family members described were group based. A few mentioned a personal telephone call or visits from the Alzheimer's Society. Alzheimer's Society staff accounts suggested interventions offered by the Alzheimer's Society were often group based, such as memory cafes, 'Singing for the Brain' or peer support groups but they also offered tailored support to try and meet individual needs. Some memory services staff talked about tailored interventions such as psychology, occupational therapy or cognitive rehabilitation but the focus group discussed CST as the main psychosocial intervention offered by that memory service, as did the the manager of that memory service when interviewed.

6.2.3 Overarching Theme 3: Context of services and stigma

The context of services within which people were offered interventions influenced uptake. What interventions were offered, when and where were discussed in all interviews. Some staff highlighted stigma as an issue. A few accounts from people with dementia and family members also suggested they felt the stigma associated with dementia.

Scheduled appointments and 'information overload'

A few joint interviews with people with dementia and family members referred to diagnostic or post-diagnostic appointments at memory and NHS services feeling rushed, being handled insensitively or the language used as hard to understand. Some focus group staff described the amount of information nurses had to try and cover during a scheduled hour long post-diagnostic appointment and how this could lead to 'information overload'. Similarly the doctor felt time was an issue within their appointments. These accounts suggest some people with dementia and family members were unable to process information offered about psychosocial interventions during these appointments, alongside the other information covered.

Resource management within dementia services

Resource management within dementia services and how this could impact on provision and uptake of interventions was an issue discussed in some staff accounts. Whilst people with dementia did not talk about this, a few family members acknowledged the impact of funding cuts on local services. Staff perspectives suggested limited resources impacted on the range

and type of interventions they could provide. Not providing transport to interventions given the difficulty some people faced travelling to intervention venues was felt by several staff to limit uptake. Interviews with people with dementia and family members indicated the importance of convenient transport to enable intervention uptake, but none talked explicitly about expecting transport to be provided.

Access and practicalities

Transport and travel to intervention venues were identified as key issues from most interviews with people with dementia and family members and staff interviews. Some people with dementia depended on family for transport and assistance to get to interventions as they were unable to travel independently. Yet some family members had other responsibilities or their own ill health to manage. Several staff were concerned about people with dementia who could not travel independently, due to cognitive, sensory or physical impairments they or family members were coping with. Some staff talked about people with dementia or family members potentially rejecting interventions because of the effort and stress associated with organising and carrying out a journey or simply the thought of it, discouraging uptake. Some staff also thought some people with dementia worried about burdening family and so declined. Poor public transport provision within the large geographical catchment areas covered by memory services was noted by some staff.

Stigma

Stigma associated with dementia was discussed by some staff and these staff thought this discouraged uptake of interventions for some. A few people with dementia and family members talked in a way that suggested stigma may have contributed to their responses to engaging with services or interventions. Some people with dementia and family members said they did not want to attend somewhere or groups with other people with dementia. It is not possible to know how much this kind of response was due to stigma or how much due to the feelings of discomfort or worry being with others with dementia engendered in themselves, but it seems reasonable to assume both could have influenced responses to interventions.

6.2.4 Overarching Theme 4: Relationships and communication

Relationships between family members and the person with dementia were pivotal to uptake. Relationships between staff and people with dementia and family members were also vital, because staff approaches to encouraging uptake was key. The sense of trust and how people communicated with each other were important components of these relationships, which appeared to facilitate uptake.

Pivotal role of the family

All interviews highlighted the pivotal role of the family members' in supporting people with dementia to access, accept offers and remain engaged in interventions. The interviews with the six people with dementia who lived alone identified that whilst four of these people were currently able to attend interventions alone, two were reliant on a family member to do so. Also it was unclear should the others no longer be able to drive or manage the journey's required to attend interventions whether they would be able to continue attending, should they wish to. These people with dementia also all talked about their families and the support, or about the limited contact and support, provided to them in their everyday lives. Most accounts highlighted that family members provided practical support and emotional support. Practical support involved supporting with travel, prompting to recall dates and times, enabling people with dementia to get ready or providing physical assistance. Emotional support included family members explaining they had persuaded or encouraged people with dementia to attend interventions when that person had been uncertain about going.

Trusting relationships and supporting people to manage feelings of fear and anxiety

Feelings of fear and anxiety about the future or about attending interventions where they might meet people with dementia were expressed by some people with dementia and family members. Some staff also talked about how people with dementia could feel like this, or be losing confidence in themselves and in social situations as dementia progressed. Some staff and some family members discussed how they tried to support people with these feelings when encouraging people with dementia to try interventions. Strategies that staff and family talked about using to communicate with people with dementia and to encourage uptake were similar. Such strategies appeared focused on trying to reduce anxiety by offering reassurance. Some family members and some staff recognised that attending an intervention group for the first time would be an unfamiliar activity, with unfamiliar people, potentially in an unfamiliar place. This could be an unsettling or anxiety provoking experience for people with dementia. Some sense of trust between people with dementia and their family members appeared to be evident when the person with dementia reported not being so keen on trying an intervention, but the family member had encouraged it. It seemed the person with dementia trusted their family member's judgment, at least to some extent and they allowed themselves to be led by this or acquiesced to their family members' decision about attending an intervention. The family members who described making such decisions seemed to do this because they thought the person with dementia would enjoy the intervention when they got there, based on their knowledge of the person and felt it was worth trying to see how the person found it. It seemed for these people, these familial

relationships could hold and tolerate these different views given their relationship history and knowledge of each other.

Whether people with dementia responded positively or negatively to intervention offers from staff also appeared related to a sense of trust in the staff and how staff had communicated with that person. One staff participant highlighted trust as an important element of the relationship between staff and people with dementia and thought this could affect uptake of CST offered by the memory service.

Respecting personal choice and being directive

Some staff discussed how they respected people's personal choice to reject interventions. In contrast, a few family members described sometimes being directive and persuading people with dementia to try an intervention even if they were not keen. Staff who discussed accepting rejection of interventions also talked about re-offering interventions at subsequent appointments. These staff considered that people may accept offers when they were emotionally ready to do so. This could occur at different points in time, and not necessarily when offers of intervention were made. Some staff talked about how this could occur when people had experienced more of the consequences of dementia on their lives or had adjusted more to having the diagnosis.

Sharing the evidence base for CST

Staff from Memory Services 1 talked about how they shared their interpretation of the evidence base for CST as a way of encouraging uptake of this intervention. They said they explained CST was recommended by NICE, that it had been found to be of as much benefit as some medications they may prescribe and worked alongside medication.

6.2.5 Overarching theme 5: Unmet needs and suggestions for services

Some areas of unmet need were identified and suggestions for services were identified from some interviews with people with dementia, family members and staff.

Ongoing attendance at existing group interventions

A few people with dementia and family members said they would like to continue to attend interventions they had already participated in such as weekly CST groups or they would like a regular programme of groups to attend.

Support for adjustment of roles post-diagnosis and emotional adjustment

One person with dementia had still been working at time of diagnosis. Her perspective was that she received no support with how to manage work post-diagnosis, other than being told to stop, which she felt to be devastating. Another person with dementia talked about

potentially volunteering as a way to meet people, as she had in the past. Such accounts suggested a need for more support tailored to the individual, which could include support to adjust work related roles or support to find meaning in other activities and roles. The psychologist wanted to develop the cognitive rehabilitation they already offered and start a group intervention to support emotional adjustment after diagnosis but reported lacking the resources to develop these. Several people with dementia and family members had talked about the shock and distress of diagnosis and it appeared they may have had unmet needs for emotional support after diagnosis.

Support with travel

A need for transport to interventions was highlighted by staff accounts and accounts from people with dementia and family members. The dependence of people with dementia on family members to get them to interventions was clear. This indicated that people without this support may struggle to access interventions offered if they cannot travel independently and transport is not available to them. Some staff suggested transport provision may increase uptake.

Venues and community based interventions

Some interviews highlighted a potential preference for venues not based on hospital sites. Perhaps these were seen as more 'normal', less stigmatising and possibly more convenient. Both memory services sites were regarded by some as problematic either for parking or travelling to. Alzheimer's Society staff acknowledged that venues such as church halls may not appeal to some people, suggesting there may be a need for some interventions to be offered in 'neutral' spaces.

Activities not targeted specifically at people with dementia

Some people with dementia talked about wanting to go on outings such as day trips, holidays and places of interest. Many also talked about previous and current interests, hobbies and activities that they enjoyed and clearly valued. There seemed to be a desire to participate in activities in the community that may or may not be aimed specifically at people with dementia but were desired because they were enjoyable and of interest. For some, the support of another person, or group, was needed to access such activities. Thus there appeared to be a need for some to have more support to access activities they would enjoy in the community.

When I asked people with dementia and family members what they would advise others living with dementia, as a way of closing the interviews, not everyone answered. Those that did answer said things similar to: 'carry on'; 'tell people so they understand if you make a mistake or are slow'; 'mix with other people'; 'try things, you don't know until you try'. Such

responses demonstrated that these people valued and recognised the importance of keeping busy and stimulated, having enjoyable experiences and connecting with other people as much as they were able.

Support for particular types of diagnosis

Two family members talked about the lack of contact or support they and the person with dementia had experienced for particular diagnoses. One of them questioned whether it would have been beneficial for the person with dementia, if they had received information about social and stimulating activities whilst diagnosed with vascular changes for some time before being diagnosed with Alzheimer's Disease, rather than after diagnosis. Another questioned the lack of contact they now had with services, given the diagnosis of vascular dementia her husband had been given.

Also one person was diagnosed with frontal temporal dementia. The husband of this person described how they were now seeing less of family and friends. He seemed concerned that people might think his wife rude, given her changed behaviour at times. Although this couple had engaged with several different intervention groups and valued these, I considered they may have unmet needs for support about how to manage the impact of dementia on their lives and maybe were at risk of increasing social isolation.

Support for the needs of particular groups

The Alzheimer's Society manager expressed the view that the needs of people from different ethnic minorities within their location and those from the LGBTQ+ community may not be met by current interventions. They also felt people with early dementia locally should be consulted, about what sort of interventions they would like provided by services.

CHAPTER SUMMARY

This chapter presented findings from triangulating all interviews completed. Consequently, four overarching themes were identified: 'Adjusting and awareness'; 'Intervention appeal and perception of benefit'; 'Context of services and stigma'; 'Relationships and communication'. These overarching themes have informed the framework summarising influences on acceptance or rejection of psychosocial interventions presented in Chapter 7 (Section 7.4) to follow, as well themes identified from both literature reviews.

Chapter 7 Discussion

In this chapter I discuss my findings in light of the evidence reviewed for this research as well as wider literature. I present my reflections about how the methods used and my own position influenced findings and the limitations of this research. Then I present a framework summarising influences on acceptance or rejection of psychosocial interventions which synthesises the findings from this research. This can be used by researchers and those working with people with dementia to identify potential influences on uptake up of interventions. Next recommendations for policy, practice and future research are made.

7.1 Discussion of key findings from empirical study and relationships to the existing literature

My research aimed to identify influences on acceptance or rejection of psychosocial interventions by people living in the community with early dementia. Sixteen people with early dementia and 15 family members were interviewed. Twelve staff were interviewed or participated in a focus group. The interventions discussed in interviews with people with dementia and family members were group CST, education and information groups, memory cafes, 'Singing for the Brain' and a life story group. The staff focus group mostly discussed group CST offered by the memory service they all worked at. Other NHS staff interviewed also talked about CST, cognitive rehabilitation, occupational therapy and psychological interventions. Alzheimer's Society staff discussed a person centred support, memory cafes, 'Singing for the Brain', peer support groups, telephone befriending and referring people to community based activities.

The key findings of my research are that acceptance or rejection of interventions was influenced by how people with dementia and their family members respond to the diagnosis, the impact of dementia on their lives and their interactions with dementia services.

Adjustment and self-awareness influenced whether people with dementia and family members felt they could benefit from interventions at the time they were offered. Staff also discussed how adjustment and self-awareness influenced acceptance or rejection of interventions. Whether the focus of the intervention appealed and whether potential benefit was perceived, either at the time or for the future also influenced uptake. However, factors outside of the individual person with dementia were also important. The service and societal

context was significant as different services offered different types of interventions. The service context influenced resources available for interventions and where interventions took place. Societal stigma associated with dementia was evident within some accounts from people with dementia and staff, and appeared to discourage some from accepting interventions. Relationships between participants with dementia and family members were vital to acceptance. Family members provided practical and emotional support. Family members' own experiences of being affected by dementia influenced their responses and influenced uptake by the participant with dementia. The relationships and communication between participants with dementia, family members and staff also influenced uptake. Positive personal interactions with staff appeared to be important facilitators of acceptance. All these influences affected readiness to engage with psychosocial interventions, by people with early dementia.

There were some similarities between the influencing factors on uptake identified out of the psychosocial intervention literature and my own research, but also differences. An important difference was that I interviewed people with dementia and family members and staff about interventions and services provided as part of usual practice. In contrast, the majority of the literature I identified focused on outcomes and effectiveness of interventions, not reasons for acceptance or rejection. The majority of this literature was also about interventions offered as part of research studies, not usual practice. The only study identified that explicitly examined uptake of an intervention was my own, based on the preliminary work completed for this PhD (34) (see Chapter 1), and the intervention involved was also part of a research study. I was able to identify some reasons for limited uptake, declining and non-engagement with interventions described within the existing literature. I also identified some literature that suggested that services did not always meet needs or preferences and that individual experiences of living with dementia appeared to influence uptake of interventions (Chapter 2). The similarities and differences between findings from my own research and the existing literature are now discussed.

7.1.1 Co-morbidities, personal, social and living circumstances

Within the research literature, co-morbidities, personal, social and living circumstances were identified as reasons for non-participation or limited engagement with interventions (for example (99,103,107,109)). In contrast, people with dementia and family members I interviewed were managing other health concerns alongside dementia and most were also attending psychosocial interventions. This contrast may be because participants in my study were all affected by early dementia whereas the reviewed literature mostly described the experiences of participants with mild to moderate dementia. Another explanation could be

the perceived burden and requirements of research participation compared to interventions in practice. For example, those managing co-morbidities may feel unable to participate in research that requires longer term participation, study visits and outcome measures compared to interventions in practice. However, my findings echoed the literature in that people described how coping with co-morbidities made participation in interventions effortful and support was needed to facilitate uptake.

Several studies reported personal, social or living circumstances as reasons why people with dementia declined or dropped out, for example, due to moving, travel plans or other commitments (for example, (99,107,114,120). Other personal commitments affecting acceptance or rejection of interventions were described by people with dementia, family members and staff in my research. These accounts and the literature identified suggests that interventions may not be perceived as offering enough benefit to be managed alongside other commitments, by some individuals.

7.1.2 Awareness and adjusting

Awareness

The literature identified offered limited insight into the impact of adjusting and awareness on recruitment to or engagement with interventions. Difficulty recruiting people with dementia who do not explicitly acknowledge their diagnosis, to research studies, may explain why this was the case. In my research, most people with dementia demonstrated some awareness of the challenges they faced and acknowledged their diagnosis. This is perhaps not surprising given they had agreed to participate in a study about dementia. However, I also found that some people with dementia may not always acknowledge their diagnosis or demonstrate awareness of their difficulties.

This phenomenon is confirmed by other research. For example, Clare et al (93,94,167) have examined and described the impact of awareness in early Alzheimer's Disease. Morris and Mograbi (168,169) have presented a model of implicit and explicit awareness to help conceptualise awareness in dementia. Clare's (93) biopsychosocial framework of awareness in early Alzheimer's Disease helped me consider concepts of awareness and emotional adjustment when considering interview accounts which described adjustment difficulties or people not acknowledging dementia. Sometimes I noted differences between how people with dementia and family members in joint interviews discussed the impact of dementia or that people with dementia demonstrated memory difficulties during the interviews but described not noticing changes in themselves associated with dementia. Clare (93) suggests that:

> *"...people fall at different points on a continuum of self-maintaining versus self-adjusting responses as they register changes, react to them, try to explain them, experience their emotional impact, and attempt to adjust"* (p.169)*.*

Clare (93) contends that denial of the diagnosis may limit explicit awareness but implicit awareness may be demonstrated. She also suggests that interactions with others, such as family members and professionals are likely influence the expression of awareness. Further, she notes that social representations and cultural narratives of dementia and everyday care-giving interactions will also likely impact on what is elicited in terms of awareness. However this model refers only to Alzheimer's Disease and not other types of dementia, which may influence how people adjust and demonstrate awareness. Uptake of and engagement with interventions could be considered a self-adjusting response. My findings suggest that psychosocial interventions may support self-adjusting responses only if they 'fit' an individual's personal interests and preferences. Whilst most people with dementia in my research acknowledged challenges they were facing and the diagnosis, a few did not explicitly acknowledge the diagnosis or use the term dementia. Despite this, these few participants had still attended group interventions specifically for people with dementia and talked about enjoying them. Also, their family members had suggested participation and taken them there. Perhaps such behaviour demonstrated implicit awareness or that explicit awareness was not necessarily a prerequisite for participating in interventions.

When recruiting for my own study, some family members explained that difficulty adjusting or not acknowledging dementia was why the person with dementia would not want to participate. Similarly, 'being unaware of diagnosis', 'denial or lack of insight into their illness' or some families not discussing dementia were listed as reasons for declining by three identified studies (109,110,120). 'Awareness of memory difficulties' was reported as an inclusion criteria for a group psychotherapy and a support group intervention in two others (105,106). Despite these reports, no other details were provided. Yet these few studies and my own research indicates that engaging people with dementia who may not explicitly demonstrate awareness is a challenge.

This challenge of engaging people with dementia who demonstrate limited awareness was echoed by staff that I interviewed. Most talked about some people with dementia having limited 'insight', or not accepting a dementia diagnosis and rejecting offers of interventions. Staff talked about how they had to respect these decisions and felt that people may adjust and accept offers of support in their own time. Yet, such staff accounts also indicated that these people may be missing opportunities for stimulation, social interaction or support that could potentially benefit them and their families. How research or clinical staff responded to encounters with those who demonstrated limited awareness was not raised within the

literature I reviewed in Chapter 2. However, other research about this does exist. For example, Clare et al (170) reviewed assessments for determining awareness and Quinn et al (171) report an assessment tool for exploring beliefs about dementia to aid provision of tailored information and support. None of the staff I interviewed discussed using structured or standardised assessments to identify extent of awareness. This may indicate that they accepted awareness difficulties and relied on their clinical reasoning to work with them.

Emotional adjustment

The main review of recent evidence about psychosocial interventions (Chapter 2 Section 2.7) identified interventions aiming to support emotional adjustment and other interventions which may assist adjustment, such as self-management and peer support. There is also a body of work about psychological therapies and other interventions to aid emotional adjustment (for example (106,172–175)). Several people with dementia and some family members in my research reported feeling worried, depressed or expressed fear for the future. Staff also described observing that some people struggled to adjust to a dementia diagnosis. This is in contrast to Carpenter et al (87) who reported no significant changes in depression or anxiety post-diagnosis in participants with dementia and their companions and that anxiety decreased after diagnostic feedback. This indicates the importance of recognising individual responses and ways of coping with a dementia diagnosis. In my research, some people with dementia and family members recognised that issues such as bereavement or family issues were impacting upon their mood, in addition to the impact of living with dementia. This further highlights the individuality of responses to diagnosis; for some diagnosis and subsequent intervention offers may be reassuring. For others, diagnosis and intervention offers may not allay feelings of anxiety or depression and further help to manage the consequences of the diagnosis may be needed.

It may also be that some people reject interventions as they feel they are coping with the challenges they are facing. Phung et al (86) questioned whether people with mild dementia lacking severe symptoms required the level of support offered by the psychosocial counselling and support intervention they evaluated. My own findings echo this suggestion, in that a few people with dementia felt they were experiencing only mild symptoms and were unsure that interventions offered were needed by them at that time. This was also a perception echoed by one family member and some staff.

In my research, most participants with dementia talked about being keen to keep busy and mentally stimulated, to get out of the house and have social contact. Many discussed community based activities that they were already involved with and how important these were to them. Such discussions suggested that remaining as independent as possible was

important to participants. This is similar to studies which reported that if interventions were perceived as supporting independence, most participants had found this positive and the interventions acceptable (103,117).

Concerns about contact with other people with dementia

Some participants with dementia and family members described not being keen to spend time with other people with dementia and gave this as a reason for declining intervention groups. Staff also described this as a response they encountered. These findings support Bunn et al's (77) comment, that whilst peer support can be beneficial it can potentially have a negative impact for some, by showing what the future may hold. However, other participants with dementia and family members I interviewed clearly valued the peer support obtained from meeting others. Not wanting to be with others with dementia was reported as a reason for non-participation in only one identified study (107).

My findings suggest awareness and emotional adjustment after diagnosis affects readiness to engage in interventions for some people, yet the impact of awareness and adjustment on uptake is an under researched area. Some degree of self-awareness and adjustment may be necessary for people with early dementia to accept interventions, particularly if interventions use the word 'dementia' in the title or staff use the word 'dementia' when discussing interventions. However, not using the word dementia could also be problematic as this is the diagnosis people and their families have been given. My own research suggests that some people did not explicitly acknowledge their diagnosis but still engaged in interventions such as group CST. Staff described respecting people's right to decline interventions for whatever reason, including when there was no explicit acknowledgement of the diagnosis or associated difficulties. However this response does not consider whether there are ways to actively influence responses or intervene to encourage participation in interventions.

7.1.3 Intervention appeal and perception of benefit

Whether interventions appealed and whether potential benefit was perceived was identified as an overarching theme in my research.

Group versus tailored interventions

Group interventions were the type of intervention most frequently raised within all the interviews I conducted. Whilst group interventions were not personalised to the individual they appealed to many of the people with dementia and family members I interviewed. Those who valued social contact, peer support, mental simulation and enjoyable activity appeared to perceive a potential benefit from participation. In contrast, the majority of

interventions within the literature I reviewed described the development and evaluation of tailored interventions for individuals with dementia or dyads. I also found that group interventions did not appeal to some of the participants with dementia and most staff described that disliking groups was a common reason given for declining. Woods et al (110) reported that a few carers expressed discomfort with groups as a reason for declining, in a study of joint reminiscence groups. Woods et al (110) also reported examples of carers withdrawing people with dementia who seemed to be enjoying the groups but the carers were less enthusiastic. The views of the people with dementia who participated in these groups was not reported. Cheston et al (105) noted that group psychotherapy would not appeal to all people with dementia, just as it would not appeal to all those without cognitive impairment. This highlights that offering the same type of intervention, whether group based or not, is unlikely to appeal everyone.

Tailoring and targeting interventions to individual need has been emphasised by other researchers (77,82,83,86). Phung et al (86) suggested that assessment should identify those people with mild dementia and carers who need intervention most. In my research, staff described the different types of interventions offered by the services they worked within. This could be viewed as services trying to respond to different needs. Memory services staff accounts suggested that generally one intervention was offered initially, at diagnosis and post-diagnosis appointments, to most people. For Memory Service 1 this was group CST. For Memory Service 2, this was an education and information group, and CST would be offered after that. In both memory services staff described other interventions, such as cognitive rehabilitation, occupational therapy and psychology, but it was unclear how many people were referred to these following diagnosis. The Alzheimer's Society staff interview suggested that their service offered several different group interventions and tailored initial assessments to try and meet individual needs by linking people with appropriate services. Thus whilst it appeared there was some variety of interventions, overall it appeared there was limited choice in practice if the intervention offered to an individual did not appeal to them.

There were some people with dementia and family members in my research who talked about visual, hearing, mobility and balance difficulties and the consequent effort it took to get out of the house. My analysis found that most of those I interviewed with physical and sensory challenges had also managed to participate in group interventions and reported enjoying them. Despite this, if an individual with dementia has difficulty seeing and hearing it seems reasonable to expect that this may lead to some uncertainty about attending group interventions, although of course participation would also depend on other factors such as

family member support, location and transport. The needs of people with dementia with sensory impairments within psychosocial interventions appears to be mostly set aside in the existing literature I identified. One exception was Mountain and Craig (84) who reported 'managing dementia alongside other conditions' as a main theme in their study about the potential content of a self-management programme.

7.1.4 Context of services and stigma

The context of service delivery was identified as an overarching theme in this research. The role of services and staff, and services not meeting needs or preferences was also identified within the literature reviewed. My research also identified how wider societal stigma could affect uptake.

Service delivery context

In my research, several staff talked about how resources and organisational decisions could impact upon interventions offered and consequent uptake. For example, staff in Memory Services 1 described an initiative trialling diagnostic clinics within primary care settings. These staff considered that referrals for group CST for people diagnosed via this route were lower than expected because GPs may not be promoting CST to the people diagnosed or that people diagnosed via this route may not wish to attend an unfamiliar service. Bunn et al (77) highlighted the role of GPs in facilitating access to services for people with dementia. Participants in my research talked about GPs referring them to memory services. My findings were that GPs are key to referrals to memory services and thus diagnosis but it may be their role did not facilitate uptake of psychosocial interventions after diagnosis. Dodd et al (176) identified an absence of post-diagnostic support from primary care led dementia services in Bristol. Such findings indicate how important local service context can be in determining what is offered and so what is accepted.

Practicalities

Practical issues associated with people accessing interventions were described as being vitally important to people with dementia by the people with dementia, family members and staff who took part in my research. Location, type of venue, and ease of travelling were all factors that encouraged or discouraged uptake. The potential benefit of an intervention could be outweighed by the stress or inconvenience of travel. Staff participants in location 1 were concerned about the lack of transport provision which they felt led some people with dementia to decline. Several studies reviewed identified similar concerns (82–85). When consulting people with dementia about a self-management programme Mountain and Craig (84) identified the importance of convenient, familiar locations such as GP practices. Thus

my findings echo such research and indicate that familiar, easy to get to and community-based venues may encourage uptake.

Stigma

One participant with dementia and family member said the person with dementia did not want to be seen attending memory services and a few described losing friends since the diagnosis or feeling self-conscious in public. Some staff raised stigma as being a reason for some people declining interventions. None of the literature I reviewed described stigma affecting engagement in interventions. However, it may be that stigma contributes to why people decline to participate, either in research studies or interventions in practice. This seems likely given other research detailing the stigma those affected by dementia can experience (177,178).

7.1.5 Relationships

Relationships were an overarching theme in my research. This included the long-term relationships between family members and the people with dementia they supported. It also embraced the relationships established between staff, people with dementia and family members. These relationships could facilitate or discourage uptake of interventions.

Importance of family members

One family member interviewed for my research was still working. Others described being recently retired or their own mental and physical health difficulties. These issues affected how available these people could be to escort the person with dementia to interventions if this was needed. Within the literature a range of challenges experienced by family carers is described. For example, Miu et al (121) reported that working family carers did not have time to participate in a joint intervention. Also, poor health of carers was cited as a reason for non-participation of dyads in several studies (109,110,119). Staff from Memory Services 1 said that family member participation was not required for the group CST interventions they offered. However they also explained that that family members were invited and in practice, mostly attended with or escorted the person with dementia. For most intervention studies I reviewed, family member participation was a requirement. Having no suitable family member to participate alongside the person with dementia was explicitly identified as a reason for exclusion in three studies (99,110,115). These studies and my own highlight the central role that family members have in supporting uptake and continued engagement.

My research found that support provided by family members, that facilitated intervention uptake, appeared practical and emotional. Practical support involved driving people with

dementia to interventions, prompting and for some, physical assistance. Emotional support involved encouraging the person with dementia to try an intervention when that person was unsure or not keen. Some family members talked about being directive or persuasive in order to get the person with dementia to attend an intervention, if they believed the person with dementia would enjoy it when they got there but beforehand were declining or uncertain about attending.

This nuanced sense of family members providing emotional support and experiencing the challenges of trying to encourage people with dementia accept interventions was rarely raised in the literature I reviewed. One study did report that caregivers found it difficult or stressful to motivate their relative with dementia to engage in the activities required by the intervention and posed this as a reason for drop-outs (116). Whether additional responsibilities placed on carers during a group reminiscence intervention for people with dementia and carers (110) and an individual CST intervention, in which carers were trained to deliver activities (109), were perceived or experienced as too burdensome, and thus affected recruitment or dropout has been questioned in two publications (109,110). In contrast, family members interviewed in my research talked about being keen to find enjoyable activities for the person with dementia or for them both as a couple. This may reflect some of the differences in the people I recruited compared to the people approached for research studies. For example, most research studies within the literature I identified included people with mild to moderate dementia, whereas participants in my research were those with described as having early dementia by themselves or others. Thus the carers in the study reporting difficulty motivating people with dementia (116) or in the studies which considered the potential burden on carers of dyad interventions (109,110) carers may have been supporting people with more moderate symptoms of dementia.

Relationships with services and staff

In their review, Bunn et al (77) suggested that therapeutic relationships between people with dementia and staff could facilitate referrals to community groups. My research supports this assertion. My research found that the relationships forged between people with dementia, family members and staff were important to uptake and engagement with services. Bunn et al (77) also identified that some studies included in their review found that attending memory services could be frightening or shocking (90,91). A few participants with dementia and their family members in my research described the way that some staff had communicated with them as being a distressing or stressful experience. For most however, the way staff communicated was described as supportive and reassuring. Personal interactions and relationships with staff pre-diagnosis, at diagnosis and post-diagnosis appeared to have influenced attitudes to engaging with services and the interventions offered.

From my research I identified some strategies that staff and family members employed to encourage uptake. Yet the strategies used to communicate an intervention offer are not identified within the existing literature. Some studies did highlight the role of staff in recruitment or in confirming the acceptability of interventions. For example: having clinician facilitators was valued by participants of a self-management group (117); recruitment was facilitated by follow-up telephone calls to people with dementia shortly after initial contact in a study of another self-management intervention (103); the need for face-to-face assessment to determine suitability and for staff to be proactive in recruiting people with dementia, as they tend not to come forward on their own initiative was noted by a study evaluating a support group (120). However, it cannot be assumed that such findings about the approach used by research staff to promote interventions in research studies would transfer to practice settings.

My own research found staff talked about using their own judgement when offering interventions. For example, the focus group staff talked about how they offered group CST to all people with mild to moderate dementia most of the time. However, they also explained some circumstances in which they may not offer CST, for example if they judged other complex needs (such as mental health issues, alcoholism, bereavement or physical ill health) needed to take priority or the person with dementia would not be able to engage with activities involved in attending. The focus group agreed that whilst they may judge a person was not suitable for CST at a particular time they would re-offer it if the person's situation or health improved. This highlights the key role front line memory services staff have as gatekeepers to provision of psychosocial interventions in practice.

7.1.6 Unmet needs and suggestions

Unmet needs and suggestions for services were identified as an overarching theme in my research. The following section discusses these with respect to the published evidence.

Needs for emotional support with adjusting to a diagnosis and living with dementia

Some people with dementia I interviewed remained distressed by their diagnosis. The psychologist I interviewed wanted to offer a group to support emotional adjustment post-diagnosis. Staff also acknowledged that some people with dementia declined interventions because they were struggling to accept or adapt to the diagnosis. The Alzheimer's Society staff reported offering support groups and there are evidence based interventions to support emotional adjustment and coping after diagnosis (for example,(86–88)). Yet, my findings suggested that there were still unmet needs for support to facilitate emotional adjustment after receiving a diagnosis.

Needs for support with valued activities

One person with dementia described being in paid employment at the time of diagnosis. Another wondered about volunteering as a way of meeting people. The literature I identified did not report interventions to address work or work related roles for people over 65, and I did not examine literature about young onset dementia where such issues might be covered. Although research about people over 65 with dementia and work appears sparse, some does exist and suggests that supporting those with early dementia over 65 with work related concerns is needed (180,181). This need is also indicated by employment statistics. For example, the number of people aged 65 and older still in employment in 2018, was 1.26 million (182). It is also estimated that if the retirement age increases to 70, the number of people still in employment who develop a dementia will be an estimated 8.5% of the total prevalence of dementia in the UK (181).

Also, most participants with dementia and all family members discussed the activities they enjoyed and wanted to keep doing. These activities were based in the community and part of their everyday lives, not interventions aimed at specifically at people with dementia. Five studies within the main review of recent evidence about psychosocial interventions (Chapter 2 section 2.7) reported interventions aiming to support people with early dementia with activities they personally identified (19,20,34,108,113). In my research, the psychologist and an occupational therapist discussed providing cognitive rehabilitation and occupational therapy to support achievement of personal goals. Alzheimer's Society staff discussed their service as aiming to identify personal needs and link people with existing community organisations or activities, if that was wanted. Potentially these types of interventions could support work related goals or community based activity. However, no people with dementia or family members in my research discussed being offered these or similar interventions. The value these participants placed on community based, non-dementia focused activity was clear and some also described increasing difficulty with doing the activities they enjoyed. Thus I inferred there were unmet needs for support to facilitate engagement in community based activities not designed specifically for people with dementia.

Needs of people living without regular family support

The key role of family members as facilitators of intervention acceptance raises questions regarding how people with dementia living alone or without regular family support can engage in interventions. Four of the six people with dementia I interviewed who lived alone were able to travel independently, two relied on family to drive and help them attend interventions. However, those who lived alone and travelled independently also talked about forgetting or getting confused about appointments. Some had not attended intervention

sessions as planned. Some interventions reported within the literature identified were designed for people with dementia alone or did not require family member participation, including a self-management group, cognitive training, a psychotherapy group or support and educational groups (96,98,103,105,107,120). Yet, participants with dementia and family members in my research did not report being offered such interventions. This suggests that such interventions have not been translated into usual practice in the settings for my research. However, group CST for people with dementia alone was offered by both NHS settings in my research in accord with national guidance (24).

Studies that described and evaluated interventions solely for the person with dementia did not discuss practicalities such as how people who cannot travel, remember appointments or get ready independently might cope with attending. This is in contrast to the staff in my research who expressed concern about how those who lived without support of families could attend interventions. There is also other research evidence that people with dementia who live alone may need additional support to engage with services (183,184). These and my own findings suggest that interventions may be rejected by people with dementia who live without regular family support or that such people may not attend even if they initially accept.

Needs for support and meaningful activity for those with non-Alzheimer's dementias and those demonstrating limited awareness

Bunn et al (77) noted that the experiences of those with Alzheimer's Disease and their families may not be directly transferrable to those with other types of dementia. Several studies within the literature I reviewed only included those with Alzheimer's Disease, and others were not specific regarding the type of dementia of participants. This means that results may not be transferable to those with different types of dementia diagnosis. For those studies which did include mixed samples, results were not disaggregated by diagnosis, suggesting intervention outcomes for different types of dementia diagnoses were not examined or reported. In my research, one husband described how behavioural changes in his wife, diagnosed with frontal temporal dementia, had led to them socialising less. Further, one family member discussed concern about the lack of monitoring for her husband diagnosed with vascular dementia. Other research has described the challenges faced by family carers supporting people with frontal temporal dementia (for example, (185)). Also a study about living well with dementia examined the impact of different types of dementia on quality of life, life satisfaction and well-being, reporting those with non-Alzheimer's Disease type dementias having a lower capability to live well (186). Such research and the

experiences of these participants both concur in that needs for support may vary depending upon specific diagnosis.

Needs for physical activity and exercise

Most of the people with dementia who were interviewed said that they would attend physical activity or exercise based interventions, if their physical health allowed them. Such responses indicate that they recognised the importance of physical activity to their wellbeing and function. Only one person, with vascular dementia, described attending an exercise group run by memory services. In contrast, within the literature I reviewed several studies evaluated interventions with physical components (102,111,114,118,119,121). The interviews I completed led me to consider that for some people with early dementia, support to engage with physical activity may be an unmet need for some or that exercise based interventions or those with a physical component could appeal to some people with early dementia.

The diverse needs of people with dementia

Only one staff participant discussed the need for interventions to engage people from minority ethnic groups and LGBTQ+ people with dementia. Within the literature about psychosocial interventions I reviewed, the needs of these populations were not discussed, apart from one study noting that participants they recruited did not reflect the diversity of the local population (120). Other research recognises that minority ethnic groups are under-represented in UK health services and thus may not access dementia services (52,187). There is also a growing recognition that needs of LGBTQ+ people with dementia are not met within dementia services (188–190). Such evidence indicates that the diverse range of people with early dementia and their needs are not being served by the kinds of psychosocial interventions described by the participants in my research.

7.2 Reflections

The aim of this research was to identify influences on acceptance or rejection of psychosocial interventions by people with early dementia living in the community and their family members. This section reflects upon the methods used (Chapter 3) and the impact of my own position as a researcher and occupational therapist upon the research process.

7.2.1 Challenges of conducting and analysing joint and solo interviews

I conducted 12 joint interviews with participants with dementia and family members and four solo interviews with people with dementia. Whilst I consider that I was able to represent the perspectives of people with dementia within most of the joint interviews, trying to elicit their perspective whilst still engaging a talkative family member was challenging at times. Although I combined the data from both solo and joint interviews for the purposes of analysis, this was because main themes identified for each of these data sets overlapped. During analysis therefore, I coded instances of where people with dementia and family members expressed different views and my post interview reflections about how each person had expressed themselves within a joint interview. This meant I could represent the different views within my findings. These methods helped me represent the perspectives of people with dementia within my findings. Managing the challenges of joint interviews with people with early dementia and family members and the analysis of that data during a reflexive qualitative research study has not been reported elsewhere, to the best of my knowledge.

Issues of recall and using prompts

I used verbal, written and visual prompts during interviews to aid recall and stimulate discussion when people with dementia had difficulty answering questions. However, most could recall some experiences of services and aspects of interventions they were offered or took part in. Verbal prompting from myself or family members often led to further recall and discussion by the person with dementia, as did using written prompts (i.e. topic guide questions and prompts printed onto paper) or using photographs of memory services, with some participants with dementia. However, it is possible that people with dementia and family members had been offered or participated in interventions they did not recall or discuss with me. This illustrates the limits and nature of recall in an interview situation. I also acknowledge that staff may not have discussed all interventions they were aware of with me. My theoretical stance acknowledges that an objective reality about a person's experience may not exist (127,128) and I chose to conduct interviews to gain participants' perspectives, to answer my research questions.

Using verbal and written prompts was effective in that participants were able to select a response and this stimulated discussion. However my choice of prompts influenced the data obtained. For example, if participants were unable to answer questions about other support they would like, I presented options of possible interventions (based on the literature and my knowledge of available interventions, such as support with physical activity, daily living tasks

or cognitive stimulation). It is possible other researchers would have selected different prompts to give and responses would be different.

7.2.2 Challenges of conducting the staff focus group and interviewing staff

The debate between staff themselves during the focus group was possibly somewhat limited and discussion focused very much on the provision of CST groups (as reported in Chapter 5 Section 5.4). This is perhaps not surprising given this memory service had a team dedicated to providing a rolling programme of CST. The discussion and interactions within the focus group may have occurred as it did for several reasons. It may be the limited time available, over a lunch break, restricted debate. Staff may have perceived me as an outsider and it is possible they wanted to present themselves and service in a positive light, to be supportive of the way the memory and CST service had been developed and operated, rather than appearing potentially critical or negative. The staff had been asked to attend by their manager, so they may have felt unable to decline participation, although study materials made clear participation was voluntary. The manager arrived and joined in 15 minutes before the end, which may have affected what staff felt able to say. The focus group was also made up of staff with different amounts experience, different lengths of service and different professional groups. This dynamic may have prevented some from expressing a different view to the rest of the group. For example less senior or less experienced staff may have felt inhibited to express a different view or question more qualified or experienced colleagues. Two of the staff (the Occupational Therapist and support worker) were members of the team providing CST groups, so it possible that other staff may have felt uncomfortable if they had wanted to question or debate the provision of CST in that service.

As most staff were interviewed during their working hours I kept to the agreed length of time for interviews. This meant, particularly for the focus group, doctor and memory services manager I did not pursue lines of questioning I would have liked to. With more time I could have asked more about what needs staff considered might be unmet for people with dementia or what other interventions they would ideally like to offer. Conducting telephone interviews facilitated participation of staff but may have limited the rapport I was able to build.

7.2.3 My own position as a researcher with a clinical background and my previous research experience

My professional background as a researcher and an occupational therapist impacted on the conduct and outcomes of this research in certain respects. A positive impact was that I understood the service delivery contexts and therefore how to identify and recruit participants for interview. However I was also aware that my role as a researcher differed to

my role as an occupational therapist. I regarded my role as a researcher within interviews required me to ask questions, listen actively and try to elicit participant views and perspectives, without offering solutions. This overlaps with but also contrasts to the role of an occupational therapist. In clinical practice I would aim to listen actively, seek service user views and perspectives but I would also be problem solving, suggesting potential strategies, activities or services. At times it was difficult for me not to do this. I felt a duty of care towards participants' needs and well-being. Yet I recognised I was not there as an occupational therapist and nor was this was why people had agreed to speak to me. Thus I did not make such suggestions within interviews. The strategy I adopted is recognised as being good practice in qualitative research; waiting to the end of the interview recording and then signposting as appropriate. For example, if people with dementia or family members had been upset I asked if they knew about support services if they had not talked about using them, whether they had looked at online resources or would consider talking to other people about how they were feeling. I did not tell participants with dementia and family members I was an occupational therapist. However, I did tell some staff participants about my clinical background when it came up in conversation as it gave me credibility. This allowed me to build rapport, although there was a risk that these staff could then make assumptions about my knowledge.

My previous research experience of recruiting and interviewing people with dementia (Chapter 1 Section 1.2) meant I knew how important it was to make a personal connection with people with dementia and family members, to establish a rapport and work with staff and family gatekeepers to recruit. However, a possible negative impact of my previous research role was my prior involvement with recruiting research participants to the VALID research programme from Memory Services 2. Although I gained permission to display recruitment materials for my study in the waiting room there, I felt more active recruitment such as involving staff as participants or asking them to recruit people with dementia would not be possible. This was because previously some staff had expressed concern to me about limited time to offer research studies within their appointments. I felt that asking for assistance with recruitment to my study at the time I needed to, was likely to be refused.

Another example of my previous research experience influencing this research was that I had noticed the use of the term 'post-diagnosis' by dementia services. Therefore I adopted it as a search term for the literature review (Chapter 2). However, I subsequently found that this term is not commonly used within research literature. Thus, I had to adapt my search terms.

There were also some limitations to this research, which are now presented.

7.3 Limitations

Convenience samples and data saturation

Purposive sampling and seeking data saturation may have led to different findings than those based on the convenience sample I obtained. A purposive sample would have involved seeking participants with a more varied range of key characteristics. However, resources were not available for such an approach nor for recruiting participants until data saturation. Participant accounts from location 1 have dominated, given I recruited more participants from that site. I recognise that the convenience sample and fieldwork settings may limit transferability or applicability of these findings. Particularly, they may not transfer to the experiences of those from diverse populations and backgrounds. However, I did obtain some variation in key characteristics within the convenience sample of participants I obtained, such as age, professional background, type of diagnosis and nature of caring relationships. For staff, I interviewed different types of professionals, obtaining a sample which broadly reflects the different kinds of staff working in and with memory services in England, as well as two staff working in the voluntary sector.

Being a solo researcher

As a PhD researcher with limited resources, my own interpretations have dominated analysis and findings. I have enhanced the credibility (162), validity and reliability of this qualitative research using methods as suggested by Silverman (95). The thematic analysis and triangulation process enabled constant comparison of codes and themes and comprehensive data treatment. Academic supervision also challenged my assumptions. However, more researchers being involved in data collection and analysis would have enabled further reflexivity and may have enhanced the credibility of this research.

The focus of my research being upon experiences of services in usual practice, compared to research literature reporting interventions offered as part of research studies

The majority of the literature I identified was about psychosocial interventions offered as part of research studies. The relevance of such literature to my research could be questioned given I interviewed participants about interventions offered in practice. However, examining the research literature enabled me to begin to determine the reasons why people with dementia and family members do not participate in interventions and gain some understanding of views about why certain interventions were acceptable or not. It seems reasonable to think that some of these reasons would be similar to those influencing responses to interventions in practice. Yet there also will be differences. For example, the

type of participants recruited to research studies may differ to those seen in practice, perhaps in terms of motivation and willingness to join interventions, severity of dementia within the early or mild to moderate experience of dementia, or other characteristics such as educational level or socio-demographic variables. Despite the limitations of the literature reviews completed, given the nature of the evidence available about uptake of interventions these reviews, alongside my own findings, contributed to a framework summarising influences on acceptance or rejection of psychosocial interventions presented next.

7.4 A framework summarising influences on acceptance or rejection of psychosocial interventions

My research has identified that there are several key influences that affect acceptance or rejection of interventions by people with early dementia.

Initially I had developed a preliminary model of readiness to engage (Chapter 2), based on the scoping literature review (Chapter 2) and secondary data analysis completed as part of the preliminary work for this PhD (34). My intention, as outlined in my research objectives (Chapter 1, Section 1.6) had been to build on this and propose a model of on readiness to engage in interventions. After completing the research I considered how to represent my findings (i.e. both the empirical findings and those from the literature) within a model. I considered I had gained understanding about the influences on acceptance and rejection of interventions but perhaps not really how people changed their attitudes or behaviour over time in terms of accepting interventions, if they had not been ready to engage. This limited what I could propose for a model of 'readiness' to engage in psychosocial interventions. Most of the people with dementia I interviewed had accepted and engaged with interventions offered. Those that expressed reticence and the two people who had not engaged with any interventions had helped me consider reasons for potential rejection. Yet this data did not really illuminate factors which may result in person moving from not being ready engage in an intervention to being ready. Similarly, the information gained from staff interviews, the staff focus group and the literature reviewed suggested potential influences on what may encourage acceptance or rejection of interventions. However, this was not data obtained from people with dementia and family members themselves or interventions implemented in practice. As discussed above (Section 7.3) implications drawn from the literature had some limitations given interventions reported were mostly offered within research contexts. Given these issues, I have presented a framework to summarise influences on acceptance or rejection of psychosocial interventions (Figure 7.1). The challenges and complexity of trying to identify a model of readiness to engage within this study are further discussed within my concluding remarks (Chapter 8).

Figure 7.1 A framework summarising influences on acceptance or rejection of psychosocial interventions after diagnosis by people living with early dementia in the community
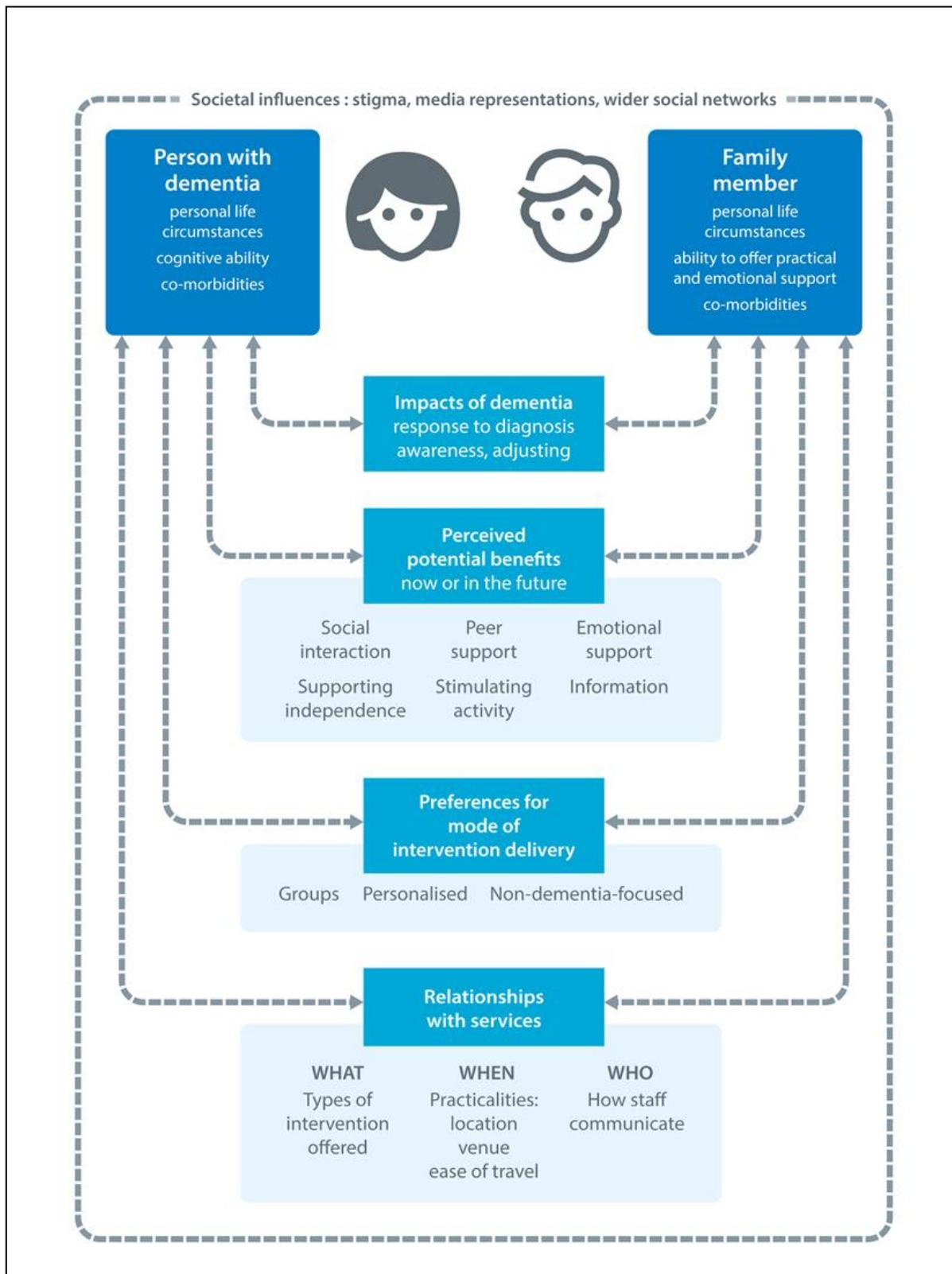
Figure 7.1 synthesises the main influences on acceptance or rejection identified by this research and aims to represent overall findings from both the empirical data and literature reviewed.

Figure 7.1 illustrates the influence of family members, staff, services and the wider context on the responses people with dementia. Both the person with dementia and the family member are represented. This is because my own research and the literature identified indicate how vital family support is to acceptance of interventions by people with dementia. However, Figure 7.1 also represents people with early dementia who live without regular family support. Further, the focus of this framework is on people with early dementia. It does not aim to represent all influences on family members their own right. Rather, this framework presents family members' relationship to and influence on the ability and willingness of the person with dementia to engage with interventions.

The main themes identified for the scoping and main literature review (Chapter 2) and the overarching themes from interviews with people with dementia, family members and staff (presented in Chapter 6) each had different themes, with different names. The language chosen to summarise findings in Figure 7.1 is an attempt to represent all findings in a way that practitioners may understand, rather than using exact overarching theme names (Chapter 6) and main themes from either literature review (Chapter 2). So, overarching theme 1 ('Adjusting and awareness') from the empirical findings is represented within the box 'Impacts of dementia' - response to diagnosis awareness, adjusting' on Figure 7.1 and this box also incorporates a scoping review theme, that individual experiences of dementia appeared to influence uptake.

Overarching theme 2 ('Intervention appeal and perceived benefit') from the empirical findings is represented by the box 'Perceived potential benefits – now or in the future'. The larger box beneath lists different kinds of perceived benefits people interviewed (people with dementia, family members and staff) discussed as well as potential benefits, intended outcomes or aims of interventions reported within the literature (i.e. social interaction, supporting independence, peer support, stimulating activity, emotional support, information). Aspects of overarching theme 2 ('Intervention appeal and perceived benefit') are also represented within the bottom two boxes in Figure 7.1 (Relationships with services and 'what when who') as issues relating to practicalities and types of intervention offered affected whether interventions appealed to people.

Overarching theme 3 ('Context of services and stigma') from the empirical findings is represented in several places in Figure 7.1. Aspects of this theme are present in the boxes 'Relationships with services', 'Preferences for mode of intervention delivery' and in line

outlining the figure, which is intended to represent the wider societal context within which intervention offers occur, including stigma. This is because overarching theme 3 incorporated aspects of all these issues; people with dementia, family members and staff talked about different types of intervention offered by services. The literature reviews also identified different types of intervention (i.e. groups, personalised).

Overarching theme 4 ('Relationships and communication') from the empirical findings is represented in several boxes in Figure 7.1. Firstly, the person with dementia and family member are represented separately, but also as linked (indicated by the arrows and lines for both people going to each box) to indicate the importance of this relationship. Also the smaller text ('ability to offer practical and emotional support') within the family member box aims to highlight the central importance family members supporting engagement in interventions. This was supported by findings from main literature review. The boxes 'Relationships with services' and the box beneath ('what' 'when' 'who') also relate to overarching theme 4 because relationships with staff and services, as well as with family members, appeared to influence uptake. These two boxes were also informed by findings from both literature reviews, which identified the importance of practicalities such as location and travel on uptake. Overarching theme 5 ('Unmet needs and suggestions for services' was predominately about suggested improvements to services and not influences on acceptance or rejection of interventions. Therefore this theme is mostly not represented within this framework. However, the phrase 'non dementia-focused' in the box 'Preferences for mode of intervention delivery' does refer to one issue incorporated into overarching theme 5; namely that many people with dementia and family members talked a lot about activities they valued that were not aimed specifically at people with dementia. My interpretation of this was that some people may need more support to access activities within the community, and that such support could be another mode of intervention delivery.

Within the empirical findings, co-morbidities were identified as important influences on the type of support people needed. For example, staff discussed how this could prevent engagement in interventions. Co-morbidities mostly did not appear to stop the people with dementia I interviewed engaging with interventions although co-morbidities did limit the kinds of activities they could engage with. The literature reviews also found that co-morbidities were often reasons for non-participation in interventions. So for these reasons, co-morbidities have been included within the 'person with dementia' and 'family member' boxes to indicate that each person may be dealing with other health issues, alongside dementia, which may influence their responses to intervention offers. Similarly, personal life circumstances (for example, moving house or not having a family member to attend an intervention) were identified as reasons for non-participation in interventions by the main

literature review. For this reason 'personal life circumstances' have been included in the 'person with dementia' and 'family boxes'.

This framework is now ready for evaluation. The framework illustrates the complex range of factors that influence decisions to accept or reject interventions and that should be considered by those providing interventions.

This framework can be used by practitioners and researchers developing new interventions or offering existing interventions, as a tool to help consider what may influence responses to interventions, by people with early dementia. It is hoped that in turn this could aid intervention development and uptake of support after diagnosis by people with early dementia living in the community.

This framework proposes that whether people with early dementia accept or reject interventions is only partially determined by the person with dementia themselves and the cognitive impairment they experience; it is also shaped by societal influences such as stigma, media representations of dementia and wider social networks.

This framework proposes an understanding of the influences on acceptance or rejection of psychosocial interventions without differentiating between the different types of dementia or the many different types of intervention.

7.5 Recommendations

7.5.1 Recommendations for policy
The following recommendations are aimed at policy makers and commissioners of health and social care services.

i) Continue to promote post-diagnostic support, evidence based psychosocial interventions and tailored support for individuals after diagnosis to enable people with early dementia to remain engaged in their communities and lives.

ii) Support awareness raising campaigns, public education and staff training initiatives to aid de-stigmatisation of dementia.

iii) Encourage healthy aging initiatives to be inclusive of those with early dementia and support them so that these people can participate along with other older people who do not have dementia; encourage dementia 'friendly' approaches so that communities, public spaces and services are inclusive for those with early dementia.

iv) Continue to promote personalised care plans for every person with dementia (5). Consider how these can be evaluated over the course of an individual's life with dementia, from the point of diagnosis on and including evaluation of access to psychosocial interventions for people with early dementia living in the community.

7.5.2 Recommendations for practice

The following recommendations are aimed at those providing services and interventions for people with early dementia after diagnosis in clinical or non-clinical settings as part of usual practice.

i) Audit current psychosocial intervention provision to enable review of the type of interventions offered to people with early dementia within a given service, when and where they are offered and where interventions take place

The proposed framework could be used as a starting point to consider topic areas for audit. For example, audits could identify key characteristics of service users who accept and decline, relating to their personal life circumstances (e.g. age, gender, caring relationships/living situation, co-morbidities, level of formal education or occupation at retirement, post code, ethnicity, type of diagnosis). Audits could also identify numbers of those who decline or accept different types of interventions or those offered in different venues.

Identifying the numbers of people offered interventions who decline and accept interventions and some of their key characteristics could help identify areas for service development.

ii) Consider enhancing the choice of interventions available through memory services and the local community and offering interventions tailored to individual needs

The framework proposed indicates that people with dementia and family carers have preferences for modes of intervention delivery and may or may not perceive potential benefits for interventions they are offered. Thus mode of delivery and intervention outcomes need to be considered when trying to engage people in interventions aiming to support them.

This research found that it is important to recognise whilst some value group interventions, others will not engage in group interventions or interventions aimed specifically at people with dementia. Some people with dementia and carers may prefer to continue with, or find new activities in their communities but need support to enable this.

Health services could pursue or develop links with community organisations that support and offer activities for the general population and older people, if this is not already happening.

This may facilitate access to non-dementia focused interventions that are nevertheless dementia 'friendly' and can support people with early dementia to participate alongside those without dementia.

Understanding individual needs and tailoring interventions to meet these is important. Interventions tailored to individual need, in addition to peer support and education groups or CST groups described by participants in this research, are needed. Tailored occupational therapy and psychology interventions or cognitive rehabilitation could be offered, if they are not already.

iii) Consider practicalities and consultation when planning interventions

The proposed framework highlights the importance of practicalities to intervention uptake. This research identified venues, location and ease of travel will affect acceptance and rejection of interventions. Familiar, community based venues may encourage uptake. Consultation with potential participants may help identify preferences.

iv) Consider how to stay in contact with those who decline interventions but may change their mind as time progresses

This research highlighted that some people with dementia and family members will decline interventions and offers of support. The proposed framework of influences on acceptance and rejection of interventions indicates the importance of relationships with services and how staff communicate with people with dementia and families to encourage engagement. If people with early dementia are advised to contact services themselves, in between or instead of scheduled review appointments they may not do so, even when in need of support. It may be that people with early dementia are more likely to accept interventions if invited in person, by letter and telephone call, particularly if personal contact and a relationship with the staff involved is established.

7.5.3 Recommendations for future research

These recommendations are aimed at those conducting dementia related research and evaluating psychosocial interventions.

Potential topics for further research with people with early dementia

i) Further research is needed to explore whether creating a model of readiness to engage would enhance understanding of this topic further as well as more research to examine reasons for acceptance and rejection of specific interventions.

In order to propose a model of readiness to engage, different study designs and sampling strategies could be helpful. For example, a longitudinal study interviewing people with dementia and family members at different points in time after diagnosis may better illuminate processes of change from not being ready to engage to a readiness to engage. Or, an ethnographic study could involve observation and interviews with people with dementia and family members using services that offer interventions after diagnosis. Sampling people who have declined interventions offered would also be necessary for this.

Further, qualitative approaches could use purposive sampling to include key characteristics (such as socio-economic status, ethnic group, educational attainment, co-morbidities, age, gender, caring relationships, and type of dementia diagnosis) to try and gain the perspectives from a wider range of people with early dementia than was possible for this research.

When evaluating or developing a specific intervention, researchers could examine whether components of the framework are represented in initial responses to the intervention and seek to identify which if any influences affect engagement in that intervention most. Such work could be used to inform recruitment and retention strategies or screening criteria for intervention studies.

Quantitative approaches could examine potential associations between key characteristics and those accepting or declining interventions. This could inform targeting of interventions or recruitment strategies in practice or research.

ii) Future research could explore with people with dementia, family members and staff whether a screening tool for staff to use or a decision aid to support discussions about psychosocial interventions would be a helpful resource or not. If such a tool was regarded as potentially worthwhile, it could be developed based on the components of the proposed framework and co-developed with staff, people with dementia and family carers.

iii) Studies evaluating interventions should report the type and severity of dementia, settings and rates of uptake by those identified as potentially eligible. If possible, reasons for declining should be collected and reported. This is important because it would help judgments about transferability and applicability for each intervention reported and enhance understanding of why some people with dementia reject interventions aiming to support them. If characteristics of those who accept or reject particular interventions and reasons for rejection or acceptance are identified, this could help researchers develop and target interventions to those most likely to accept them and thus benefit.

iv) More research is needed to examine readiness to engage with interventions that require behaviour change from people with early dementia and their family members. This is important because my research indicated that different interventions are perceived as offering different potential benefits. What encourages an individual feel ready to engage with a CST group programme, or a memory cafe, for example, may be different to what encourages them to engage with cognitive rehabilitation, psychological or occupational therapy interventions which can involve trying to change behaviour using strategies suggested. Such research could also aid understanding about what influences positive outcomes for particular interventions.

v) Research examining intervention outcomes focused on quality of life, well-being and social participation as well as cognitive function and independence with activities of daily living appear important areas for future research. This research found activities without a dementia focus were important to the people with early dementia and family members I interviewed. This suggests the importance of co-producing interventions with people with early dementia and family members, as well as seeking feedback about the acceptability or experience of existing interventions. This is important to try and ensure that interventions are addressing issues of concern to those affected by early dementia.

vi) Research into the impact of awareness and adjustment on uptake and engagement in interventions is needed. As the framework indicates, awareness and adjustment, influences acceptance and rejection of interventions. Increased understanding of these issues is important to support practice. How staff work with people demonstrating impaired awareness or those having difficulty adjusting to the diagnosis could be examined to identify current and good practice. Similarly, examining how family members support relatives who demonstrate impaired awareness or adjustment difficulties could enhance understanding and identify ways to support families.

vii) Researching the impact of different models of post-diagnostic support currently offered within and outside of health care and memory services is needed. For example, the impact of psychosocial interventions provided by memory services compared to interventions being offered or provided within primary care or community settings, on uptake and outcomes of different interventions could be evaluated. The impact of different professional groups or types of practitioners (such as GPs, Occupational Therapists, Nurses, support workers or other dementia practitioners) promoting interventions in memory services and other settings could also be examined. This research identified few published accounts of interventions delivered in usual practice, rather than as part of research studies. Identifying examples of

good practice and whether they could be adopted more widely could enhance post diagnostic support services.

vii) More research is needed to develop and evaluate interventions for people with dementia from diverse backgrounds and with diverse needs.

Methods for future research with people with early dementia

i) Studies reporting joint interviews should describe why such interviews were completed, how researchers agreed to do interviews jointly with participants and how they were conducted. Reporting methods used to support people with dementia express their views within interviews and to analyse different accounts expressed within joint interviews would enable learning to be shared.

ii) Observational or ethnographic studies within clinic and service settings could examine how practitioners communicate with people with dementia and family members in practice when offering psychosocial interventions. How staff communicate is highlighted as an influence on uptake by the model of readiness to engage proposed. As this research obtained interview accounts, observational methods could enhance understanding of other influences on uptake of interventions, allowing different and complimentary perspectives to be represented.

iii) Longitudinal case studies (191) could examine in detail the impact of different settings and contexts on uptake and readiness to engage in interventions.

iv) A range of practical participant validation methods for involving people with early dementia are needed. These need to be engaging and manageable for such participants. For example: holding workshops to seek feedback on initial key findings with participants or seeking new recruits to gain feedback on key findings could be options; returning to participants one or two days after interview with a summary of key points to ask if these felt a fair representation of the interview could be another alternative. The burden on participants, impact on recruitment and how new data generated will be interpreted and analysed would need consideration.

CHAPTER SUMMARY

This chapter discussed my own empirical research findings in light of published evidence about psychosocial interventions and some of the wider literature about dementia. I presented my reflections about the challenges of conducting and analysing joint and solo interviews with people with dementia and family members. Limitations to this research were also discussed. A framework summarising influences on acceptance and rejection of psychosocial interventions was proposed for researchers and those providing services to consider and informed recommendations made for policy, practice and research. These recommendations emphasised the need for tailored support to meet the diverse needs of people with early dementia and for further research to examine reasons for uptake or rejection of interventions offered after diagnosis. The following and final chapter presents my conclusions.

Chapter 8 Conclusion

This final chapter outlines the unique and original contribution this study makes to the field of psychosocial intervention dementia research and presents my conclusions about the process and outcome of this research.

In summary, this study involved interviews with 16 people with dementia (either alone or with a family member/s to support them during interview), twelve staff and two literature reviews. Overall findings were that acceptance or rejection of interventions by people with early dementia was influenced by a complex interplay of factors. The influences on acceptance or rejection of interventions involved people's responses to the diagnosis and how they felt they were coping. What kinds of interventions were offered to them by their local services, the relationships with staff built with people and societal stigma also affected uptake. It seemed interventions may not always be perceived as supportive by people with dementia or family members, despite the intention. Whether activities involved in interventions appealed to people or not and whether people perceived a potential benefit at the time intervention is offered or for the future was key. Further, support from family members was vital. Most people with dementia interviewed for this study did have a family member supporting them to attend interventions. Some did not and, those people did indicate struggles with managing to attend intervention appointments or travel. This led me to question the needs of people with early dementia without support to attend interventions if they are unable to do this independently and how services can reach out to and try to engage those who live without regular support.

This is the first study to focus explicitly on the topic of acceptance and rejection of psychosocial interventions by people with early dementia, to the best of my knowledge. This study is thus a unique contribution to the field of psychosocial intervention dementia research. The question about what influences people with early dementia to accept or reject interventions provided by services is important because health and other services provide various psychosocial interventions in practice, aiming to support people affected by dementia. Health policy encourages the provision of post-diagnostic support, and psychosocial interventions are one way of offering such support.

The framework proposed in Chapter 7 is also an original contribution. The framework summarises the main influences on acceptance and rejection of interventions by people with

early dementia, based on knowledge generated from interviews completed with people with dementia (with family members or alone) and staff as well as relevant evidence from published literature. It is hoped that this framework can have resonance beyond those individuals I interviewed, to others affected by early dementia and for practitioners and researchers to consider when they are designing, offering or providing interventions.

This research demonstrates the complexity of this topic, raising new questions and highlighting the need for further research in this area. For example, whilst I created a summary framework of influences on acceptance and rejection, I could not confidently propose a model of readiness to engage as originally intended, as noted in Chapter 7 Section 7.4. I now question whether seeking to identify a model of readiness to engage in interventions by people with early dementia in order to assist those developing or providing interventions for those with early dementia is possible and the most appropriate research methods to try and establish this. My findings lead me to ask whether it is 'simply' that an individual with dementia, as for any other individual without dementia, may reject interventions that do not appeal to them. Do pre-existing factors and personal circumstances mean individuals will engage when they wish and that there is little that practitioners can do to influence this? However, if services are in practice, offering interventions aiming to support those affected by dementia I consider it remains important to examine this complex topic further, particularly if the uptake of interventions offered is variable or low.

I also now consider whether the concept of 'readiness to engage' contains within it an over emphasis on the individual, the person with dementia, being ready or not ready to engage with an intervention, as if this is something they personally should aim to change or influence. Perhaps, an alternative question or emphasis should be on examining whether or not services are ready to engage with people with early dementia and how.

Case study approaches (191) could allow the context within which people with early dementia consider interventions to be studied in more detail, as well as their individual motivations. Further, it may be necessary to interview people with dementia and observe them, family members and staff offering interventions, all at different time points after diagnosis to ascertain whether or not and how people change from not being ready to being ready to engage with an intervention. This may best be done in relation to one specific intervention. I identified that people may accept an intervention initially but may never attend or may attend a few sessions and drop out. A person with dementia may reject an intervention because they or their family member are not ready to engage at that particular time but this may change. My findings underlined the issue of timing, i.e. when an intervention is offered to people seems important, but is currently unclear. Whether people

perceived benefit either immediately or regarded interventions as inferring potential benefits for them in the future did seem an important influence on their readiness and willingness to try an intervention. In order to benefit from interventions there is likely to be a window of opportunity in which to engage people with early dementia but precisely defining such a window was not possible within this research ad merits further explanation.

When interviewing people about the interventions they had been offered people with dementia and their family members often talked a lot about activities they do in their lives. Whether it was seeing friends and family or participating in community groups, keeping going with these kinds of activities seemed, for the people I interviewed, very important. Many, but not all, of those I interviewed also seemed to really value attending intervention groups specifically aimed at people with dementia provided by services. These findings led me to ask what dementia services, or other health and community services do to support people with early dementia to engage in the activities they want to do. It may be that for people with early dementia, attending interventions offered by dementia specific services may not always be a priority, alongside other activities in their lives.

This study also clearly demonstrated the feasibility and value of seeking the views of people with early dementia themselves about topics which affect them. Whilst I was hopeful that people with dementia I interviewed would be able to participate in the interviews, I had also been uncertain about whether asking them to reflect on and recall past events, given cognitive difficulties associated with dementia, would generate relevant data. I considered talking about their acceptance or rejection of interventions may be too abstract a subject and thus possibly difficult for people with dementia to discuss. My experience of interviewing these people with early dementia showed me how very able most were to talk candidly and give their views. At times, I did need to clarify what I was asking, use prompts from myself or family members or change my approach. Not every person with dementia could answer every question I asked, some needed support to express themselves within interviews but others needed little prompting or support. I needed to be patient and allow time for people to process questions and formulate their answers.

The interviews showed me how each person had different verbal communication abilities (for example, some people struggled to find words, some did not appear to, some lost their train of thought whilst talking and benefitted from reminders, others did not, some gave long answers, some were quite tangential, others gave short answers). This variability amongst this sample of people, all of whom had been diagnosed within the last two years, highlights the need for researchers and practitioners to really consider how they can support

communication with individuals living with dementia. It also highlights the same need for practitioners in health and service settings, where people with being dementia are invited to to participate in an intervention or receive some kind of support. If people feel at ease, are encouraged and supported to communicate it becomes easier to build a relationship and identify the kind of support or interventions they will consider. However, to identify appropriate communication supports takes time and preparation for each conversation.

Further, where conversations take place may be important: I interviewed people at home where I think they felt comfortable. This may always not be the case in clinical or service environments where interventions may be offered. This study highlights the value of interviewing people with dementia in their own homes or settings of their choice as a valuable method for gaining their perspectives and accounts in detail. The length and conduct of interviews was led by the abilities and personalities of the people with dementia. The data generated from these interviews, I believe, enabled these people's views and experiences to be explored during conversation with me in a way that would not be possible using other methods such as observation in a clinic or service settings. Observations of people with dementia in clinical or service settings may not have enabled people with dementia feel as comfortable and relaxed.

This research also contributes to the field of reflexive qualitative research conducted with people with dementia. I have been transparent about the challenges of conducting joint interviews, as I experienced them. I was transparent about how I coded and analysed the joint interviews to try and examine how the person with dementia expressed themselves within joint interviews and whether I felt I had managed to elicit and represent the perspectives of people with dementia themselves or not. I hope this in turn can enable readers of this thesis consider the challenges and benefits of engaging people with dementia in joint and solo interviews and how to analyse and represent the data obtained.

Findings also suggest some differences and similarities about the engagement of people with dementia in interventions that are part of research studies and how people may respond to interventions offered in practice. The research literature reviewed focused mainly on the effectiveness of, development of, or piloting of interventions. Although a few studies identified in the initial scoping review reported experiences of post diagnostic support services from the perspective of people with dementia and carers (82,83) these did not specifically refer to psychosocial interventions. A few studies from the main literature review also reported interventions offered in practice settings (for example (100,107) but did not discuss uptake or initial engagement specifically. However, most studies reviewed reported numbers who declined to participate and some gave reasons why. Some themes from the

research literature were similar to aspects of my empirical findings (for example, other health issues, the key role of carers, intervention characteristics not being perceived as meeting needs, dementia related characteristics). However, the burden of research participation may discourage participate in research (147) whereas interventions in practice may possibly be perceived as less burdensome. Recruiting people with dementia to psychosocial intervention studies is challenging (23) whereas, in practice, it may be that people with dementia are more easily reached. It may be people with dementia who participate research are not representative of the wider population of people with dementia who would be offered interventions in practice. However, there appears limited data to support this assertion as data collected about people with dementia offered interventions in practice does not appear to be in the public domain or is likely limited. It may also be that practitioner judgement and clinical reasoning informs staff judgements about who to invite to interventions in practice, compared to staff being guided by strict screening protocols in research studies. The methods used to search the literature were systematic and replicable. Given this study was the first to research this topic area, combining evidence from both the literature identified and data from the interviews within a summary framework appears a worthwhile first step.

A difference between the empirical findings and the literature reviewed was that in the convenience sample of people with dementia (with or without a family member) and staff I interviewed, none discussed personalised interventions (such as cognitive rehabilitation or other tailored approaches to supporting dyads). Yet, these featured in much of the literature I reviewed. It is not clear from this study why that may be. Many of the people with dementia, family members and staff talked about Cognitive Stimulation Therapy groups (CST). CST is recommended in national guidelines (24). It may be that some NHS services have prioritised delivery of this intervention and consequently perceive other interventions as having a less robust evidence base. Enquiry into how evidence based interventions make their way into dementia services and the potential impact of guidelines on the provision of post-diagnostic support and psychosocial interventions offered by NHS services is needed. Implementation studies may be needed to explore this issue (192,193) or action research that involves staff and service users i.e. people affected by dementia who may be offered interventions by their local services (for example (194)).

In conclusion, this study has highlighted the value of seeking the views of people with dementia directly, the plurality and individual nature of living with dementia and so the challenge of providing services or interventions to this population. There are questions to be asked about which services are best placed to offer psychosocial interventions to people with living with early dementia in the community, and what the role of specialist NHS memory services should be after diagnosis. It may be some psychosocial interventions could

be offered outside of medical or clinical settings and a greater focus placed on supporting people to engage in their everyday lives indicated. It may be that specialist services such as NHS memory services or the Alzheimer's Society could focus on supporting those with more moderate symptoms or specific needs such as anxiety and depression, rather than offering interventions to all people with early dementia, if they do. Other services within the community could perhaps be better supported to enable the continued engagement of people with early dementia remain participating in activities of their choice. Seeking the views of those affected by early dementia and involving them in redesigning services that offer interventions, or developing interventions to encourage engagement in community life is paramount.

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APPENDICES

BMJ Open

Recruiting hard to reach populations to studies: breaking the silence: an example from a study that recruited people with dementia

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ABSTRACT

Objective To share the challenges of recruiting people with dementia to studies, using experiences from one recently completed trial as an exemplar.

Background Research publications always cite participant numbers but the effort expended to achieve the sample size is rarely reported, even when the study involved recruiting a hard to reach population. A multisite study of a psychosocial intervention for people with dementia illustrates the challenges. This study recruited 468 'dyads' (a person with dementia and a family carer together) from 15 sites but the time taken to achieve this was longer than originally estimated. This led to a study extension and the need for additional sites. Recruitment data revealed that certain sites were more successful than others, but why? Can the knowledge gained be used to inform other studies?

Methods Secondary analysis of routinely collected recruitment data from three purposefully selected sites was examined to understand the strategies used and identify successful approaches.

Findings At all three sites, the pool of potential recruits funnelled to a few participants. It took two sites 18 months longer than the third to achieve recruitment numbers despite additional efforts. Explanations given by potential participants for declining to take part included ill health, reporting they were 'managing', time constraints, adjusting to a diagnosis of dementia and burden of study procedures.

Conclusions Successful recruitment of people with dementia to studies, as one example of a hard to reach group, requires multiple strategies and close working between researchers and clinical services. It requires a detailed understanding of the needs and perspectives of the specific population and knowledge about how individuals can be supported to participate in research. Experiences of recruitment should be disseminated so that knowledge generated can be used to inform the planning and implementation of future research studies.

INTRODUCTION

Research publications report numbers of participants and usually numbers screened and excluded. Yet the effort expended to achieve required sample sizes is rarely reported even when studies recruited hard to reach populations. We contend that transparency about the challenges involved in recruiting hard-to-access populations and potential solutions to the challenges is required to enable future clinical studies to plan and recruit in a time-efficient and cost-effective manner.

Dementia research is a global clinical and research priority.[1 2] In England, it has been proposed that to meet future study requirements, the number of people with dementia participating in dementia research should increase from 4.5% of those diagnosed with dementia to 10%.[3] Yet, it is well documented that people with dementia are a hard to reach population and recruiting the numbers needed for research is challenging.[4-7] This is particularly so for psychosocial research which requires the participant with dementia and often a family carer to consent to possible involvement in an intervention aimed at both people. These studies, like the example used in this article, can be perceived as being particularly demanding for potential recruits.

The example we use here is based on recruitment to one study ('Valuing Active Life in Dementia' (VALID)). VALID first adapted and developed an occupational therapy intervention for community-dwelling people with dementia and their family carers (dyads). The intervention aimed to facilitate independence, meaningful activity, quality of life for the person and carer competence. VALID then evaluated the clinical and cost-effectiveness of the intervention compared with usual care. All participants were asked to complete validated instruments at baseline, 3-month and 6-month follow-up. This involved each person completing questionnaires at home, with a researcher. The intervention involved up to 10 home or

community-based sessions with dyads. These involved the dyad working together with an occupational therapist to identify personal goals and practising suggested strategies to achieve them. Further details of the VALID study are described elsewhere.[8]

Study inclusion criteria involved recruiting the dyad. The time taken to achieve the target sample (n=480) was longer than originally estimated and contributed towards a study extension and the resource-intensive requirement to recruit further sites. Over the course of the study, it became evident that certain of the 15 sites were more successful at achieving recruitment targets than others. As researchers involved in the management and delivery of this study, we wanted to identify the reasons for this.

The objective of this paper is to share the challenges of recruiting people with dementia to studies, using our experiences from the VALID study[8] as an exemplar.

METHODS

A secondary analysis of recruitment data routinely collected by 3 of 15 participating sites was conducted to compare differences and similarities between recruitment at these sites, the strategies used to promote recruitment and the outcomes of such strategies. The three sites (A, B and C) were selected because they had participated in the VALID pilot study which indicated a substantial pool of potentially eligible participants reportedly available at each site and they had the resources available to support this secondary analysis. Anonymised information was extracted from data routinely collected at each of these sites via 'trial management logs'. Sites A and B used EXCEL for this purpose, site C site used their own, existing recruitment database. Each site collected core information to enable screening for study inclusion criteria. This included records of all contacts with potential recruits during screening and recruitment and those made following recruitment for the duration of the participants' involvement in the study. Researcher notes, which recorded the reasons provided by potential participants for accepting, declining or ineligibility were also analysed and categorised. The data were tabulated at each site to enable the description of the recruitment process, strategies and outcomes. Cross-site analysis then compared these findings.

FINDINGS
Site characteristics

Site A served four diverse London boroughs. Site B was a Northern city with a predominately urban population. Site C served an urban and rural population in the North of England. Sites A and C had experience of recruiting to and delivery of psychosocial intervention dementia research. This was the first large-scale psychosocial intervention dementia study site B had participated in.

Recruitment targets

Recruitment targets for each site were based on the findings of a pilot study at each of these three sites which examined the feasibility of study procedures and recruitment. This, as well as investigator experiences of successful recruitment to psychosocial dementia research and numbers of occupational therapists trained and available to deliver the intervention, indicated the numbers each site could be expected to recruit. The number, type and experience of staff dedicated to recruitment varied at each site.

Sites A, B and C had targets of 90, 80 and 60, respectively. Initially, recruitment was scheduled for 18 months but was extended when recruitment proved slower than anticipated. As shown in table 1, site C recruited over the agreed target within the planned time frame. In comparison, sites A and B took 18 months longer to recruit 92% and 91%, respectively, of their target numbers.

Identified recruitment strategies

The differences and similarities in recruitment strategies at the three sites are summarised in table 2. Similar strategies were employed at all three sites with National Health Service (NHS) memory services being the main source of participants at each. Memory services provide specialist diagnostic services and postdiagnostic support. At sites A and B, but not at site C, researchers maintained a regular presence in memory service clinics so that they were readily available to talk to potential recruits. At site B, a research nurse also prescreened clinical records to identify potentially eligible people to memory service clinicians in advance of routine appointments. Also, at this site, only study information was displayed at general practitioner (GP) practices at which this memory service offered postdiagnostic follow-up appointments. At site C, multidisciplinary clinical team meetings were used to identify potential recruits, this was not noted at the other two sites. At sites A and C, recruitment was extended into the non-statutory sector (charities and organisations supporting people affected by dementia). A further

Table 1 Recruitment targets, number of potential dyads, number of dyads consented, percentage of target achieved, and time taken, by site

	Site A	Site B	Site C
Target (dyads)	90	80	60
Potential dyads identified during study recruitment	332	233	144
Total number consented (% of potential dyads identified that 'converted' into participants)	83 (25%)	73 (31%)	73 (51%)
% of target achieved	92%	91%	122% (13 dyads above target)
Length of time taken to recruit (months)	29	29	11

NB. percentages rounded to the nearest whole number

240

Table 2 Recruitment strategies used to identify potential participants, by site

	Site A	Site B	Site C
Recruitment strategy			
Within NHS site memory services			
Direct referral by memory services clinicians	✓	✓	✓
Regular presence in memory services clinics by researchers	✓	✓	–
Attendance at psychosocial intervention groups by researchers	✓	✓	✓
'Pre' screening of clinical records by a research nurse	–	✓	–
Leaflets and posters displayed	✓	✓	✓
Ad-hoc mail outs targeting potentially eligible participants choosing to attend follow-up appointments offered at local GP practices, instead of memory services at the hospital	–	✓	–
Within other services provided by the NHS site			
Potential participants identified by within multidisciplinary clinical meetings	–	–	✓
Occupational therapists delivering the intervention identifying potential participants	✓	✓	✓
Attendance at clinical team business meetings by researchers	✓	–	✓
Leaflets and posters displayed (other NHS Trust locations)	–	✓	✓
Research team made contact with people who had participated in other studies previously and had agreed to be contacted about future studies	✓	–	✓
Involvement of other NHS providers			
Information displayed in GP practices associated with memory services	–	✓	–
Patient identification Centre in another NHS Trust	–	✓	–
Non-NHS			
Attendance at community groups by research staff	✓	–	✓
Study promoted by researchers at local events	✓	✓	✓
One mail out via non-statutory sector organisation / sending non-statutory sector organisation staff study information	✓	–	✓
'Join Dementia Research' (JDR) (https://www.joindementiaresearch.nihr.ac.uk): an online resource that enables people to register interest in participating in dementia research and thereby be 'matched' to relevant studies. Researchers then contact them directly. People who expressed interest living within the sites' locality, were sent information when JDR became active at each site.	✓	✓	✓

GP, general practitioner; NHS, National Health Service.

strategy, at sites A and C, was to contact eligible people who had taken part in previous dementia research studies. Site C identified 15 additional potential recruits this way and site A identified 5. This route was not available in site B as no dementia research whereby people with dementia were asked for consent to be contacted about other research studies had taken place .

Reasons for exclusion

The main reasons documented for exclusion are presented in table 3. The two sites which took the longest to recruit their target numbers (A and B) also had larger numbers of people excluded due to being ineligible or unwilling to participate.

As table 4 shows, reasons given by those unwilling or unable to participate (when provided) were recorded at all sites. It was not possible from the available records to determine if it was the person with dementia, the family carer or both members of the dyad who declined to participate. The numbers of potential participants excluded due to being unable or unwilling to participate at sites A and B outnumbered those excluded for all other reasons including individuals that researchers had been unable to contact. Site C recorded the lowest number of people being unable or unwilling to participate. The 'other reasons' for the declining category included adjusting to the dementia diagnosis, participation being perceived to

Table 3 Main reasons recorded by research staff for exclusion by site

Reason for exclusion	Site A	Site B	Site C
Study inclusion criteria not met or exclusion criteria identified*	53 (21%)	18 (11%)	8 (11%)
No contact made	64 (26%)	28 (18%)	12 (17%)
'Unable or unwilling to participate' recorded as reason	132 (53%)	114 (71%)	51 (72%)
Total excluded	249	160	71

*Inclusion criteria not met/exclusion criteria identified included person with dementia not living in the community, not having capacity to consent, not score 0.5–2 on clinical dementia rating scale[18] or no family carer available to participate, a dyad participated in an earlier phase of the study or was participating in another intervention study or was unable to communicate fluently in English.

be a burden and personal circumstances (such as travel plans, moving house or bereavement).

DISCUSSION

This secondary analysis of routinely collected recruitment data for one study involving people with dementia was highly informative. We found that successful recruitment of people with dementia, as one example of a hard to reach group, requires multiple strategies and necessitates close working between researchers and clinical services. All sites found recruitment to this psychosocial intervention study to be challenging, but one site did achieve the target numbers of participants within the allocated time.

Table 4 Recorded explanations for being unable or unwilling to participate, by site

Main explanation (if given) for being unable or unwilling to participate	Site A	Site B	Site C
Declined participation, no reason recorded	53 (40%)	50 (44%)	12 (24%)
Physical ill health of either person	6 (5%)	15 (13%)	4 (8%)
'Managing fine' reported	11 (8%)	6 (5%)	11 (22%)
Time constraints reported	25 (19%)	24 (21%)	11 (22%)
Other reasons recorded	37 (28%)	19 (17%)	13 (25%)
Total potential participants recorded as unable or unwilling to participate	132	114	51

NB percentages rounded to the nearest whole number.

Our findings showed the original pool of people available for recruitment quickly funnelled to a few at each site for a variety of reasons. Initial optimism regarding the potential pool of participants was fuelled by optimistic clinician estimates and our desire as researchers to be persuaded by these figures. It was also underscored by the need to work within the limitations set by the funder, as a better recruitment rate would be less costly and contribute towards a successful study. Alternatively, less optimistic recruitment estimates would raise doubts about study viability. This poses questions about how researchers can realistically estimate the recruitment efforts required for any study. We would like to encourage debate about this issue.

Novel contribution

We interrogated the challenges of recruiting to one dementia study and argue for routine sharing of such experiences between researchers. We identified several key issues that appeared to affect recruitment in this study, which are likely to have implications for research conducted with other hard to reach groups. Possible reasons for recruitment challenges are organisational and individual.

Organisational factors

Research site experience of recruitment to and running similar studies appears to be a critical issue. The exemplar in this paper involved recruiting a hard to reach population to a complex psychosocial intervention study, which potentially required significant time investment by participants. Although sites A and C had established working relationships between clinicians and site-based researchers, the most successful recruitment site (C) was also able to identify potentially eligible participants within multidisciplinary clinical meetings. This demonstrated active rather than passive clinical engagement in the study and consequently, the identification of those who were most appropriate to approach. Due to previous experience of running such studies, both sites A and C approached people who had previously consented to be contacted for potential participation in other studies as one of their strategies. Site C was able to approach greater numbers this way. For site B, this was not possible. Staff at sites A and C were both experienced in delivering psychosocial intervention dementia research but recruited at different rates which was not expected. This analysis confirms that no single factor is responsible for recruitment, rather effective recruitment depends on the interplay between a combination of factors. Different populations, demographics or research fatigue may have influenced the different recruitment outcomes. The number of other research studies running at sites may also have affected the engagement of NHS research and clinical services. An additional factor affecting recruitment for psychosocial intervention studies such as this is the requirement for staff to deliver the intervention. The recruitment of participants has to be matched with

the availability and sustainability of this workforce. In this study, sometimes recruitment at sites was temporarily halted until an occupational therapist was available to deliver the intervention. It is well known that clinical staff can act as gatekeepers, they may be unclear about the benefits of research projects, worry about overburdening patients or fear patients may feel pressurised to participate.[6] However, it seems that site C managed to overcome these issues and make research a positive aspect of clinical care.

Individual factors

Alongside these organisational challenges, individual factors affected the responses of potential participants. It is well documented that people with dementia can be hard to reach.[4 7 9] Various reasons for this have been identified, including family carers wishing to protect people with dementia from potentially stressful situations or burden.[10] Although we could not determine whether this was the case from the available data, it seems likely this could be a contributory factor to recruitment challenges, for example; some of the records examined noted family carers reporting the person with dementia did not accept their diagnosis, or became upset when dementia was mentioned. Linguistic difficulties or people with dementia lacking capacity to consent have also been noted as reasons that can lead to recruitment difficulties for this hard to reach group[4] and in this exemplar, people with dementia were excluded for those reasons. Researcher notes indicated some potential participants reported they had 'too much on', suggesting participation was perceived by some as burdensome without offering enough potential benefit to compensate for this. Other researchers have found that studies can be perceived as time-consuming particularly for adult children or that people with dementia may be concerned about burdening relatives with the role of study partner.[11 12] Reasons recorded for declining may also have been polite refusals obscuring other reasons for declining which remain unknown. The message here is that researchers need to understand and be able to respond appropriately to the needs and preferences of the specific hard to reach group. Generic research training is not sufficient.

Possible recruitment solutions

We suggest the following as potential strategies to improve recruitment efforts for future research studies involving hard to reach populations.

First, making the potential benefits of research transparent to potential participants is important, as is the involvement of clinical services and family carers. Law et al[13] found that people with dementia wanted to be asked directly and involvement in research can lead to feeling valued and sense of being able to contribute. Asking the person with the condition directly about their potential involvement, if they have the capacity to provide this, is essential. As our findings demonstrate, there are also advantages in ensuring that relevant services are on board

and perceive engagement in the research to be relevant to them and the people that they work with. But, as Iliffe et al[14] noted, the need to support research infrastructure for psychosocial dementia research remains.

Second, a national research registry whereby people with dementia and caregivers are asked for consent to be approached for research participation can help identify potential recruits.[7 15] Further, some NHS trusts in England are developing systems whereby patients can be asked for their permission to be contacted about research at any point in their care pathway. If staff are persuaded by the potential benefits of research, then this strategy may aid recruitment.

Third, transparent reporting of recruitment strategies and how many people were initially identified as being potentially eligible including the contexts within which recruitment took place will support knowledge sharing. Analysis of recruitment methods should ideally be built into study designs to allow detailed reflection as an intrinsic part of large studies involving hardtoreach groups. There is a need for research to examine the impact of the type of dementia diagnosis, age, comorbidities, socioeconomic status, ethnicity, education or type of caring relationship, as well as different recruitment methods, on participation or non-participation, in studies to further illuminate influences on recruitment.

The analysis used as an exemplar in this article was completed once the study had been designed and commenced and had limitations. For example, resources meant we were able to examine recruitment experiences at these three sites only, rather than all 15. Also, we cannot comment on the effectiveness of any single recruitment strategy used at each site or the relationship of key characteristics of participants on recruitment outcomes. Despite this, what we can say is that it seems an interplay of organisational and individual factors influenced recruitment outcomes and this needs to be considered in future studies. We contend that completing similar analyses as studies progress, if building this into the initial plan is not feasible, is still worthwhile. Such work can enable learning to be shared, across study sites and with other research teams.

Fourth, comprehensive researcher understanding of the perspectives and needs, including any special requirements of the specific hard to reach population being studied, is necessary. For example, identifying ways to engage people with cognitive impairments, perhaps alongside comorbidities, sensory and physical impairments that limit the social participation of people with dementia[16] may facilitate recruitment. Communication style is important and may need adapting.[17] This may well require additional researcher training and on-going support.

CONCLUSIONS

Successful recruitment of people from hard to reach groups, such as people with dementia, requires multiple

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strategies and necessitates close working between researchers and relevant services. It requires a detailed understanding of the needs and perspectives of the specific population and application of knowledge regarding how individuals can be supported to participate in research. Reporting the evaluation of recruitment strategies and experiences should be an expected output from large studies. This would enhance understanding about how to enable hard to reach populations to participate in studies.

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Appendix 1.2 *(right retained to publish this material)*

Influences on uptake of a community occupational therapy intervention for people with dementia and their family carers

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Abstract

Introduction: Health policy promotes living well with dementia. Occupational therapists deliver interventions to support people with dementia and family carers to live well. This study aimed at identifying influences on uptake of a community occupational therapy intervention by people with dementia and carers, as little evidence about this topic exists.

Method: Seventeen semi-structured, paired interviews with people with dementia and carers were conducted as part of the 'Valuing Active Life in Dementia' research programme. A secondary, qualitative analysis of these interviews explored influences on uptake of the intervention.

Findings: Four main themes were identified: 'Grabbing at straws and keen to take part'; 'We're trying to put a routine in'; 'We didn't know what to expect', and 'Give it a go'. Factors identified as potentially influencing uptake included whether the intervention was perceived as potentially meeting needs for support and activity, and whether participants were struggling to adjust or cope.

Conclusion: Despite limited expectations or apprehension, uptake of this intervention was demonstrated. Understanding why people with dementia and carers accept intervention offers can inform what occupational therapists provide and how it is offered. Further research is required to determine the occupational therapy interventions people with dementia and carers might find supportive at different stages of the disease trajectory.

Keywords

Dementia, psychosocial intervention, occupational therapy, secondary analysis, qualitative research, community

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Introduction

Living well with dementia is promoted nationally and internationally (Department of Health, 2009; Global Action Against Dementia, 2013). UK health policy recommends post-diagnostic support to enable people to live well in the community for as long as possible (Department of Health, 2015; NHS England, 2017; Scottish Government, 2017; Welsh Government, 2016). This is important given that a cure for dementia is not imminent. A growing evidence base demonstrates that psychosocial interventions can benefit people with mild to moderate dementia by improving cognition, improving performance in valued activities or daily living skills, maintaining quality of life or aiding carer coping (Clare et al., 2011, 2017; Graff et al., 2006, 2007; Spector et al., 2003; Streater et al., 2016).

Occupational therapists offer interventions to people living with mild to moderate dementia and family carers (Streater et al., 2016; Swinson et al., 2016; Yuill and Hollis, 2011). The National Institute for Clinical Excellence and Social Care Institute for Excellence (2006) recommended occupational therapists provide skills training for activities of daily living. Also, the Memory Services National Accreditation Programme recommends people with dementia have access to

occupational therapy and other psychosocial interventions such as reminiscence, life story work or cognitive stimulation therapy, for the cognitive, emotional, occupational and functional aspects of dementia (Hodge et al., 2016). Such interventions can be delivered by occupational therapists. The focus on the benefits of non-pharmacological interventions provides occupational therapists with an opportunity to deliver services that improve lives and the experience of dementia (Collier and Pool, 2016). Understanding what may influence uptake of such interventions is important if people with dementia and their carers are to benefit from what occupational therapists can offer. Yet what supports the uptake of such

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interventions, specifically by people with mild to moderate dementia living in the community and their family carers, is poorly understood, and limited research about this topic exists. 'Uptake' in this paper is defined as initial acceptance of an offer, intervention, support or services, rather than continued engagement or adherence to an intervention over time.

The Valuing Active Life in Dementia (VALID) research programme

The VALID research programme adapted, developed and evaluated the clinical effectiveness and cost-effectiveness of a community occupational therapy intervention for people with mild to moderate dementia and their family carers. It is the largest study of occupational therapy for people with dementia ever conducted in the UK. The intervention was based on one initially developed by Graff et al. (2006) in the Netherlands. The intervention was designed to promote independence, meaningful activity and quality of life for people in the mild to moderate stages of dementia and family carers. In the UK, intervention involved approximately 10 tailored sessions with an occupational therapist in people's homes or local communities. Assessment included both interviews with participants and structured observation of activity. This was followed by personalised goal-setting, based upon assessment findings, then supported practice and strategy use to achieve goals. Further details of the intervention and associated research are described elsewhere (Wenborn et al., 2016). This paper reports a secondary, qualitative analysis of post-intervention, semi-structured interviews conducted with people with dementia and their carers in the UK, as part of the VALID programme's development phase, which involved adapting the Dutch intervention to the UK setting.

Literature review

There is evidence demonstrating the potential of occupational therapy to support people with mild to moderate dementia, and family carers, in the community (Graff et al., 2006, 2007). There is also evidence for other psychosocial interventions for people with dementia that can be delivered by occupational therapists to support cognitive function (Spector et al., 2003; Streater et al., 2016; Yuill and Harris, 2011), achievement of meaningful goals (Clare et al., 2011, 2017), self-management (Sprange et al., 2015) or tailoring activities to reduce behavioural symptoms and functional dependence (Gitlin et al., 2018). Research about community service use and needs of people with dementia in the UK has reported outcomes or experiences of service use but not explicitly discussed influences on uptake of services (Corbett et al., 2012; Gilbert et al., 2017; Gorska et al., 2013; Innes et al., 2014). Chrisp et al. (2012) identified influences on the decision to first engage with the healthcare system by examining case studies of 20 carers of people with dementia attending UK memory clinics. This highlighted that the person with dementia not accepting symptoms, not wanting

involvement of healthcare professionals and family resistance could all constrain initial service engagement. Conversely, carers taking action and responding to crises supported engagement. Much of this research involved carers, but not both the carer and person with dementia (Chrisp et al., 2012; Gilbert et al., 2017). Evaluations of post-diagnostic support interventions reported by Gorska et al. (2013) and Innes et al. (2014) did involve both people with dementia and family carers. These interventions were found not always to have met needs or preferences. Concerns highlighted were the lack of alternative options to day care, locality, travel costs (Innes et al., 2014) and poor coordination of services and lack of staff continuity (Górska et al., 2013). Services offered at distant locations or in unfamiliar environments have also been reported as being stressful and eroding independence (Mountain and Craig, 2012). Overall, within this UK research, occupational therapy is not discussed specifically. Although Chrisp et al. (2012) described memory service provision as staffed by occupational therapists and consultant psychiatrists, influences on uptake or engagement with these specific services were not explicitly reported.

Gitlin et al.'s (2018) programme for carers was provided by occupational therapists in the USA, and the authors discussed whether carers being unable to continue with activities was a possible reason why positive effects were not maintained, but did not discuss influences on initial uptake. Gitlin and Rose (2014) examined carer readiness to use strategies to modify behaviours of concern as part of an intervention delivered by occupational therapists. A rating system modelled on the trans-theoretical model (Prochaska et al., 1992) was developed to reflect readiness to engage in strategies. The authors suggested that understanding caregiver readiness and factors associated with its change may be important considerations in psychosocial interventions. Although applied to carers only, the application of the trans-theoretical model (Prochaska et al., 1992) and concept of readiness to use strategies, in relation to dementia and psychosocial intervention, appears unique.

Also, the severity of dementia of the people with dementia being supported is not always described (for example, Chrisp et al., 2012; Gilbert et al., 2017; Gitlin and Rose, 2014). Thus, it is not possible to know what proportion of the samples experienced mild to moderate symptoms of dementia. Therefore, despite some research in this area, there appears to be an absence of research focused on what may facilitate uptake of occupational therapy, or other psychosocial interventions, specifically aimed at people with mild to moderate dementia and their carers, in the community, in the UK. The secondary analysis of post-intervention interviews reported in this paper therefore aims to contribute to the evidence gap in this area.

Study aims

Within the context of the larger VALID programme's development phase, the aim of the interviews reported in this paper was to examine the acceptability of the intervention for participants in the UK and to inform its

adaptation, prior to a randomised controlled trial. Using these interviews as a secondary data source, the aim of the analysis reported here was to:

1. Identify and explore influences on uptake of the VALID community occupational therapy intervention by people with mild to moderate dementia and their family carers.
2. Identify implications for occupational therapy practice and research.

Method

Secondary data, in the form of semi-structured paired interviews conducted with people with dementia and their carers, after they had participated in the community occupational therapy intervention, were analysed. Using pre-existing data is a valuable research method which can provide new insights into existing data and help investigate new research questions (Heaton, 2004; Lewis and Nicholls, 2014). The adequacy of the original data for this secondary analysis was carefully considered, as recommended by Lewis and Nicholls (2014). The interviews were originally conducted to examine the acceptability of the VALID intervention for participants in the UK. The decision to carry out a secondary analysis was informed by a recognition that non-linear responses are typical in qualitative interviews. Given this, it seemed reasonable to explore whether participants discussed information relevant to issues of uptake when being interviewed about the acceptability of the intervention. Also, given the limited evidence about uptake of occupational therapy interventions by this client group, exploring existing, publicly funded research data seemed worthwhile.

Recruitment

Participants were recruited to participate in the occupational therapy intervention from two NHS sites in England as part of the VALID programme's development phase; inclusion criteria for this are outlined in Figure 1. During this development phase, all participants were offered the intervention. Information about the intervention and research participation was provided to potential participants by clinicians working in NHS memory services or community mental health services. These included nurses, doctors, clinical psychologists and occupational therapists. Researchers then contacted potential participants, visiting them to obtain signed informed consent before the intervention began. Approximately two weeks after intervention completion, participants were telephoned and asked if they would agree to be interviewed. Eligible participants for these qualitative interviews were pairs willing to be interviewed together, who had all previously consented to be contacted by the research team, and were within two weeks of intervention completion.

There were 130 pairs who participated in the intervention during the VALID programme's development phase, at three UK sites. The programme initially planned a purposive sample, including a range of characteristics (such as age, gender, caring relationship and banding of occupational therapists delivering the intervention). However, the programme also required that interviews occur two weeks post-intervention, given some participants may struggle with memory. Also, the programme's timeline required progression onto a pilot trial. This meant seeking a purposive sample was not possible in practice. Therefore, a convenience sample was obtained by the VALID programme, made up of intervention participants who had agreed to be interviewed. All those who agreed to be interviewed were interviewed, resulting in 17 interviews. It is not known how many were approached in total or how many declined. The 17 pairs who gave interviews were drawn from a pool of 92 pairs, from two of the sites. One site's participants (38 pairs) could not be approached for interview as, by the time necessary ethical amendments were obtained, they had all completed intervention more than two weeks previously.

People with dementia:
- Diagnosis of dementia: between 0.5–2 on the Clinical Dementia Rating scale (CDR)[1]
- Capacity to give informed consent to participate
- Living in own home or sheltered accommodation
- Receives regular support of two hours a week or more from a family carer (friend relative or neighbour)
- Family carer agrees to take part in the intervention
- Speak and understand English

Family carers/other supporters:
- 18-years-old or above
- Capacity to give informed consent to participate
- Provide support 2 hours a week or more
- Willing and able to take part with the person they support
- Speak and understand English

[1] The CDR is a rating scale used to indicate severity of dementia as mild, moderate or severe (Morris, 1993)

Figure 1. Inclusion criteria for participants in the VALID research programme (development phase).
VALID: valuing active life in dementia.

Ethical issues

NHS ethical approval was obtained for the primary data collection as part of the VALID research programme protocol in 2012 (NRES Committee Yorkshire & The Humber, REC reference: 12/YH/0492). A substantial amendment to gain ethical approval for using these interviews in this secondary analysis was obtained in 2015 (NRES Committee London-Camberwell-St Giles, REC reference: 14/LO/0736).

Capacity for people with dementia to consent to participate in the VALID research programme and these post-intervention interviews was assessed according to the key tenets of the Mental Capacity Act (2005). That is, participants were able to understand, weigh up and retain information long enough to make a decision and communicate their decision about participation.

Participants

The convenience sample obtained was made up of 34 people: 17 people with dementia, interviewed together with 17 family carers (see Table 1 for sample characteristics). The secondary analysis reported in this paper was completed on all of the 17 interviews obtained by the VALID research programme.

Table 1. Main characteristics of interview participants.

Gender	
Female	7
Male	10
Type of relationship	
Spousal relationship	12
Parent–child relationship	4
Friend	1
Type of dementia	
Alzheimer Disease	11
Vascular dementia	1
Mixed type dementia	2
Missing data	3
Severity of dementia[a]	
Mild	7
Moderate	5
Missing data	5

[a]Rating from the clinical dementia rating scale (CDR) (Morris, 1993)

Data collection

The 17 interviews were conducted by members of the VALID research team, including the first author (who completed three). Length of interviews was not recorded for the total sample. Interviews were held with the person with dementia and their family carer, together, mostly in the homes of the people with dementia. Paired interviews were organised because the intervention required both people, participating together. Interviews were semi-structured, guided by an indicative topic guide (see summary in Figure 2).

All participants provided written informed consent at the time of interview. All interviews were audio-recorded and professionally transcribed. Interviewers checked the transcripts for accuracy of transcription.

Data analysis

Thematic analysis, based on Braun and Clarke (2006), was conducted. Table 2 presents the different phases of analysis completed.

The first author led the thematic analysis, discussing coding and theme development with co-authors during the course of the analysis. NVIVO 10 software was used to store and organise data. To ensure quality, the data were handled comprehensively, that is, all transcripts were coded, all coded data tabulated, iterative analysis was conducted to create codes and themes, identifying patterns across and within transcripts and interrogating the data for accounts which did not fit into main themes (Silverman, 2010).

Findings

Four main themes and two sub-themes were identified. The first was about how uptake was influenced by the impact of dementia on people who wanted support to adjust or cope with symptoms. Within this, a sub-theme emerged related to the timing of the intervention offer

Experience of intervention	
	• What did you think about the intervention after you had taken part in it?
	• What did you expect when you agreed to the intervention?
	• Was what happened different to what you expected?
	• Did you get the support and help you needed from the intervention?
Timing	
	• What do you think about the timing of the intervention / did it happen at about the right time, or not?
Changes to the intervention	
	• Are there any suggestions you would make?
	• Would you recommend it to other people?

Figure 2. Summary of the indicative topic guide.

Table 2. Phases of thematic analysis (adapted from Braun and Clarke, 2006).

Phase 1	Familiarisation	Each transcript read several times and notes made about content and ideas for initial codes
Phase 2	Generating initial codes	List of initial codes produced, applied to each transcript, list edited iteratively until all relevant data coded[a]
Phase 3	Searching for themes	Codes grouped into potential themes; coded extracts tabulated to help identify themes
Phase 4	Reviewing themes	Groupings of codes and themes adjusted; sub-themes identified when grouped codes related to an overall theme but also needed specific attention
Phase 5	Defining and naming themes	Confirming theme content; decision made to use quotes from participants as theme names to engage readers
Phase 6	Reporting	Selection and presentation of most salient themes and sub-themes in this paper

[a]This process was 'theory driven' (Braun and Clarke, 2006: 88) as a result of asking particular questions of the data, for example what did people say that appeared relevant to their uptake of the intervention.

being important to uptake. The second theme concerned whether people were looking for new activities or whether they felt they had enough activity. A sub-theme identified that previous experience of other interventions may influence uptake of this or future interventions. The third theme was about the limited initial expectations people appeared to have about the intervention. The final theme was about positive attitudes towards trying the intervention, even though some felt uncertain or worried about participation. These themes and sub-themes are now presented, alongside illustrative quotes from participants (identified by interview number, as interviews were paired).

Theme 1: 'Grabbing at straws and keen to take part' – impact of dementia and wanting support

A key theme related to the impact of dementia on people's lives. Participants appeared to be receptive to the intervention when they were struggling to adjust to the diagnosis or cope with symptoms such as memory difficulties, lack of initiative or reduced activity levels. These quotations illustrate how some people struggled to come to terms with diagnosis or cope with symptoms, which seemed to make them receptive to the intervention offer.

> Wife (family carer): She [the occupational therapist] helped us at an appropriate time because we were both very distressed when we got the news and talking to the OT she did really help.
>
> Husband (with dementia): The same really, it was a vulnerable time...[We were having] difficulty in making sense of it all and what the implications were...She [the occupational therapist] did not play it down but she didn't...whereas it was a bit doom and gloom at this end, that lifted us and so we got to look forward to seeing her.
> (Interview 5)

When discussing her response to the offer of intervention and the timing of this, another wife explained how she struggled to cope with her husband's impaired ability to initiate activity, saying:

> Wife (family carer): Well, for me, I suppose I was grabbing at straws really and I was very very keen to take part.
> (Interview 15)

Sub-theme: 'Sooner rather than later' – offering intervention early post-diagnosis. The timing of the intervention offer also seemed to influence uptake, alongside people's experiences of adjustment, symptoms or coping. For most, it was important to offer the intervention early after diagnosis. The following quotation illustrates this preference:

> Wife (family carer): I think she [the occupational therapist] came at the right time...rather sooner than later.
> (Interview 4)

However, there was one example of participants feeling that the intervention may have been offered a little early, because the person with dementia had been confused between the different services offered post-diagnosis.

> Person with dementia: Yes, I think it was a bit too much of a rush.
>
> Daughter (family carer): Because you was doing the memory clinic thing and then you kept getting them mixed up.
>
> Person with dementia: I did.
>
> Daughter: Because there was so many new people all coming along and I think, you know...maybe doing the 10 week memory clinic thing and then after that maybe [having the intervention].
>
> Person with dementia: Yes.
> (Interview 2)

Theme 2: 'We're trying to put a routine in' – finding pleasurable and regular activity

This theme was about what people wanted to do and whether they were looking for new activities (for the

person with dementia, or both people together). For those who wanted to establish a new activity, or maintain one, this encouraged receptiveness towards the intervention. The following quotation highlights how this carer wanted to establish another social activity as part of her mother's routine:

> Daughter (family carer): She [the occupational therapist] took you to the club didn't she?
>
> Person with dementia: She did yes, yes.
>
> Daughter: She took her a few times…cause my mum already goes to one club… but we said that she needed more, 'cause we're trying to put a routine in so we've found that's a good thing.
> (Interview 12)

Sub-theme: 'Experience of other interventions'. Some people referred to positive experiences with other psychosocial interventions, provided by the NHS, social care or voluntary sector. The following quotation illustrates the impact of a positive previous experience of intervention, leading to receptiveness towards other potential offers of intervention:

> Person with dementia: When I went to the Memory Clinic for 10 weeks…I enjoyed those, it was nice meeting other people and talking to others but whether there's a chance of doing that again, I don't know.
> (Interview 2)

For others it seemed they felt they were busy enough and did not feel a need for this intervention. The following quotation illustrates the influence of other interventions and activities being valued, leading to this person feeling less receptive to the intervention offered:

> Wife (family carer): We had decided we weren't going to go on it [the intervention] really because we thought, well we are going out regular, we are going to all these memory cafes, we are doing several things, we are joining in with all that, and I really didn't think it would make a lot of difference actually.
> (Interview 14)

Theme 3: 'We didn't know what to expect' – limited expectations of intervention

This theme was about the limited initial expectations expressed about this intervention, by most of this sample. There were many examples of people saying things similar to 'we didn't have any expectations', or 'we didn't know what to expect', for example:

> Husband (with dementia): I had no preconceived ideas at all about it.
>
> Wife (family carer): I was very nervous but she [the occupational therapist] soon made us feel at ease.

> Husband: I had no preconceived ideas at all about what it would be.
> (Interview 5)

Despite these limited expectations, some participants, and all family carers, expressed the desire for emotional support, and/or education and information, to help them understand symptoms, what to expect in the future or available services. So, although they had limited expectations or understanding of what this occupational therapy intervention might offer, they hoped to receive this sort of support, if not from this intervention then from other services.

A few people in the sample did express clearer expectations, which influenced their uptake of the intervention. For example:

> Wife (family carer): I was very excited about the idea of an OT coming into the house and I thought that the OT was going to lead activities… which I am sure would have been very, very productive.
> (Interview 15)

Theme 4: 'Give it a go' – positive attitudes

This theme was about having a positive attitude that facilitated a willingness to try the intervention. When asked whether they would recommend the intervention to other people, many talked about 'giving it a go'. This attitude went alongside limited expectations or understanding of what the intervention might involve, or apprehension, and, for all participants, no guarantee of a positive outcome.

> Daughter (family carer): I was very, not nervous but we were dubious of having somebody we didn't know every week, but my husband and I discussed it and we said it has been offered to us and we said we would try anything that is offered to us to help, and I am so glad that we did.
> (Interview 7)

However, there were a few examples of people not wanting support, or of one person in the couple appearing reticent, initially, about the intervention, but accepting the offer nevertheless. Although all these people did accept the intervention, such accounts suggest that subsequent engagement in the intervention may be influenced by this perspective. The following quotation highlights perhaps a personal disposition, of not wanting to discuss personal issues, but may also highlight dementia stigma. In this case, the interviewer asked if the person would recommend the intervention to others, and the person replied:

> Person with dementia: Yes I would, but then again it depends on the circumstances concerned, you know? I don't discuss anything like you have been, I won't discuss…I don't speak to my neighbours around

here, I would rather keep myself to myself. I know it's a poor attitude, but that's how it is.
(Interview 1)

In the full transcript of this interview, the person with dementia voices distrust of people visiting. It was unclear whether this was a symptom of dementia or a long-standing concern. Another person with dementia, when asked about whether intervention had been offered at about the right time, demonstrated some reticence about uptake, saying:

Person with dementia: Oh dear, I don't know really. I mean to say, I suppose so, I don't know. Was it a bit early I would say I mean, I am not conscious of having any memory difficulties really.

Husband (family carer): No, you have had a few difficulties.

Person with dementia: Well there you are, other people notice but it is difficult for me to say.
(Interview 17)

This analysis identified potential influences on uptake of this occupational therapy intervention as people wanting support, because they were struggling to adjust and/or cope with symptoms of dementia, and wanting to establish or maintain meaningful activities. Limited expectations did not prevent uptake in this sample and an attitude of 'give it a go', despite limited expectations of what intervention could offer, appeared to encourage uptake.

Discussion

This is the first UK study that has tried to identify influences on uptake of community occupational therapy by people with mild to moderate dementia specifically and their family carers together. This secondary analysis aimed to identify and explore influences on uptake within these 17 semi-structured interviews. Potential influences were identified. Findings suggest that uptake was influenced by participants wanting support, struggling to cope with symptoms, adjustment to the diagnosis, wanting activities to engage in and an attitude of being willing to give the intervention 'a go', despite uncertainty, apprehension and/or limited expectations. Most participants considered that this intervention should be offered early post-diagnosis. Although the sample all participated in the intervention, some ambivalence about uptake was expressed by a few within the sample. For some, ambivalence related to uncertainty about what was involved, or having to accept the involvement of a professional within their life and home. Also, someone known and trusted may have influenced uptake; for example, where participants knew the professional concerned. The altruistic value placed on being asked to participate in research may also have influenced uptake.

Whilst limited research exists in the UK about uptake of occupational therapy interventions offered to both people with mild to moderate dementia and their family carers together, there are some studies evaluating or discussing post-diagnostic interventions. These highlight locality, travel and day care being the only option as concerns (Górska et al., 2013; Innes et al., 2014; Mountain and Craig, 2012) These issues were not identified in this study, perhaps because this intervention was predominantly delivered in people's homes. It may be that this positively influenced uptake, as people did not have to consider travel and its associated effort, potential stress and costs. This analysis identified concerns about managing the impact of dementia on everyday life, wanting support, both emotional and educational, and activities for the person with dementia to engage in alone or together with others. It may be that the carers' responses to such concerns were central to uptake, similar to Chrisp et al.'s (2012) finding that initial engagement with services was supported when carers took action or when crises triggered engagement. Although the carers in this study did not report crises explicitly, they did discuss difficulties and coping with symptoms.

Research about community-based dementia services has often only involved carers (Chrisp et al., 2012; Gilbert et al., 2017), and even where interventions involved both the person with dementia and the family carer, the research reported carer accounts only and did not discuss influences on initial uptake (Gitlin and Rose, 2014; Gitlin et al., 2018). In contrast, the VALID programme's decision to carry out paired interviews, and this secondary analysis to identify influences on uptake, represent attempts to seek the perspectives of both people involved in a paired intervention. During these interviews, there were occasions where accounts about dementia and the need for intervention differed between the pair. Whilst all this sample participated in intervention, a few accounts suggested a reticence on the part of the person with dementia to accept the offer of intervention initially, compared to their carer. Chrisp et al. (2012) found initial engagement with services could be constrained by carers feeling the person with dementia did not accept or acknowledge dementia-related symptoms. Other researchers note divergent understandings between people with dementia and carers, as well as within individuals (Lishman et al., 2016; Robinson et al., 2005). Such divergent perspectives may influence responses to offers of occupational therapy, or other psychosocial interventions.

Implications for practice and research

To help inform practice, further research is needed to enhance understanding about why people with mild to moderate dementia and their carers may accept or reject the offers of interventions occupational therapists offer. Such research is required so people with dementia and their carers can benefit from the evidence-based interventions available (Clare et al., 2017; Gitlin et al., 2018; Graff et al., 2006; Sprange et al., 2015; Streater et al., 2016). Occupational therapists need to be confident in methods for motivating people with dementia to participate in therapy (Collier and Pool, 2016) and how to respond to

people's needs at different stages of dementia. Gitlin and Rose's (2014) work on carer readiness to use strategies could be applied to people with mild to moderate dementia, to examine influences on their readiness to engage in occupational therapy or other psychosocial interventions that require uptake and continued engagement from both people. Further research or service evaluations could explore whether monitoring or less intensive interventions allow professionals to build relationships over time, encouraging uptake, and audit could examine potential reasons for declining interventions. Qualitative research, using interview, observational or focus group methods could further explore the perspectives of both people with dementia and their carers about adjustment, coping and support needs. Such research could enhance understanding about what occupational therapy interventions, or other post-diagnostic support, these people would want and feel ready to engage with.

Limitations

The limitations of this secondary analysis include findings being based on a convenience sample of participants from the VALID research programme. The views of those who did not complete intervention, or more variation in sample characteristics (such as caring relationship, age, dementia type) were not obtained. Total numbers of those approached for interview and those who declined, as well as length of interview, were not recorded. This sample only captures the views and perspectives of those who opted in to be interviewed and who chose to participate in the intervention, which excluded people who did not speak or understand English. This secondary analysis cannot offer insight into why people rejected offers of intervention. Purposive sampling to achieve maximum variation and/or seeking further interviews until data saturation was reached may have resulted in additional codes or themes. However, after coding all 17 transcripts new codes were not identified. Participant validation of analysis did not take place, although this is a method suggested to potentially enhance credibility (Lewis et al., 2014). The time and resources available for this doctoral research and the time between data collection and secondary analysis meant this was not feasible. The first author developed the codes and themes, which were discussed with all authors, but more than one person coding a proportion of transcripts can enhance credibility.

Conducting paired interviews with the person with dementia and their family carer together could be viewed as a limitation. Family carer accounts did dominate; in all the interviews, the carer spoke more than the person with dementia. Some difficulties with recall and remaining alert were observed in the person with dementia during interviews. Understanding the extent to which the person with dementia's response was influenced or 'led' by the carer was not possible, as the majority were conducted by other researchers and as a consequence body language and eye contact could not be taken into account. However, interviewing both people together does represent an attempt to seek perspectives from people with dementia themselves, about an intervention they were involved in.

Conclusion

This secondary analysis of 17 existing qualitative interviews with people with dementia and family carers, who participated in a community occupational therapy intervention in the UK, identified some preliminary ideas about influences on uptake of this intervention. These included participants wanting support, and a willingness to 'give it a go' despite uncertainty, apprehension and limited expectations. More research is needed to examine why people with mild to moderate dementia and family carers may or may not be ready to engage in interventions aiming to contribute to their quality of life, and what occupational therapists can do to facilitate uptake. Such information could assist with the development of new interventions to meet people's needs at different stages of the disease trajectory.

Key findings

- Uptake of occupational therapy by people with dementia may be influenced by each person's adjustment, coping or support needs
- To facilitate uptake, occupational therapists need to respond to these influences

What the study has added

This is the first study to try and identify influences on uptake of community occupational therapy by people in the UK with mild to moderate dementia and their family carers.

Research ethics

Ethical permission for the primary data collection undertaken as part of the VALID research programme was obtained from the NRES Committee Yorkshire & The Humber, REC reference: 12/YH/0492, in 2012. Ethical permission for the secondary data analysis completed for this study was obtained as a substantial amendment to the VALID research programme protocol, from the NRES Committee London-Camberwell-St Giles, REC reference: 14/LO/0736, in 2015.

Consent

All participants provided written informed consent to be interviewed as part of the VALID research programme. A substantial amendment to gain approval for using these interviews in the secondary analysis, completed for this study (part of the VALID research programme), was obtained from the NRES Committee London-Camberwell-St Giles (REC reference: 14/LO/0736).

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Appendices for Chapter 2

Appendix 2.1 Example of search strategy for scoping literature review

Database: PsycINFO <1806 to October Week 2 2015>

Search Strategy: (with suggested terms & mapped to subject headings)

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1   Dementia, Multi-Infarct/ or dementia*.mp. or Dementia/ or Frontotemporal Dementia/ (54611)

2   limit 1 to english language (50529)

3   Dementia/ or Alzheimer Disease/ or alzheimer*.mp. (63539)

4   limit 3 to english language (60330)

5   "Quality of Life"/ or psychosocial.mp. (120222)

6   limit 5 to english language (109751)

7   Psychological Techniques/ or Signal Detection, Psychological/ or Feedback, Psychological/ or Psychological Tests/ or Resilience, Psychological/ or Extinction, Psychological/ or Stress, Psychological/ or Psychological Theory/ or Interview, Psychological/ or Anticipation, Psychological/ or Adaptation, Psychological/ or psychological.mp. or Sexual Dysfunctions, Psychological/ or Models, Psychological/ (314218)

8   limit 7 to english language (276527)

9   Social Stigma/ or Social Support/ or Social Media/ or Social Conformity/ or Social Planning/ or Social Behavior/ or Social Identification/ or Social Adjustment/ or Social Isolation/ or Social Security/ or Social Facilitation/ or Social Problems/ or Social Perception/ or Social Responsibility/ or Social Marketing/ or Social Dominance/ or Social Norms/ or Social Desirability/ or Social Skills/ or Social Values/ or "Social Determinants of Health"/ or Social Mobility/ or Hierarchy, Social/ or Social Distance/ or Social Networking/ or Social Sciences/ or Social Conditions/ or Social Welfare/ or Social Capital/ or Social Control Policies/ or Social Discrimination/ or Social Environment/ or social.mp. or Social Control, Formal/ or Social Change/ or Social Theory/ or Social Work Department, Hospital/ or Social Justice/ or Social Class/ (714748)

10   limit 9 to english language (661046)

11   "quality of life".mp. or "Quality of Life"/ (53728)

12   limit 11 to english language (49689)

13   intervention*.mp. or Early Medical Intervention/ or Crisis Intervention/ or Intervention Studies/ (278887)

14   limit 13 to english language (263015)

15   treatment.mp. or Therapeutics/ (541328)

16   limit 15 to english language (499239)

17   Therapeutics/ or Therapy, Computer-Assisted/ or therap*.mp. (449141)

18   limit 17 to english language (405848)

19   Rehabilitation Centers/ or "Recovery of Function"/ or rehab*.mp. or Rehabilitation/ (78478)

20   limit 19 to english language (72969)

21   support.mp. (362976)

22   limit 21 to english language (347111)

23   Program Evaluation/ or program*.mp. or Program Development/ (339563)

24   limit 23 to english language (324059)

25   programme*.mp. (33027)

26   limit 25 to english language (30925)

27   "after diagnos* ".mp. (1332)

28   limit 27 to english language (1248)

29   "post diagnostic ".mp. (36)

30   limit 29 to english language (34)

31   "post diagnosis".mp. (374)

32   limit 31 to english language (357)

33   2 or 4 (73900)

34   6 or 8 or 10 or 12 (920302)

35   14 or 16 or 18 or 20 or 22 or 24 or 26 (1290476)

36   28 or 30 or 32 (1591)

37   33 and 34 and 35 and 36 (15)

38   from 37 keep 2,4-7,9,12,15 (8)

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Appendix 2.2. Flowchart of study selection process for scoping literature review

Electronic database searches
MEDLINE (n= 36) PsychINFO (N= 15)
Cumulative Index to Nursing & Allied Health Literature (CINAHL) (N=58)
Total search results combined N=109

Total citations after duplicates removed N= 92

92 records (title and/or abstract) screened

Total rejected N=69

23 articles identified for full text reading [2 not obtained]

21 full text articles assessed for inclusion

13 full text articles excluded.
Primary reason for exclusion:
- Not relevant to scoping question (i.e. influences on take up not identified) =5
- Sample characteristics (i.e. not mild to moderate dementia &/or community living or judgement made sample unlikely to meet criteria) = 5
- Commentary/opinion = 3

8 articles included for charting

Appendix 2.3 Stages for a scoping review and how these were adapted for the review of recent evidence

Stages for a scoping review (79)		How stages were adapted for review of recent evidence reported in Chapter 2
Stage 1	Research question for scoping review	Research question for examination of studies: *"Do any of the studies included by Keogh et al* (14) *and identified by other methods report issues which influence acceptance or rejection of psychosocial interventions?"*
Stage 2	Identifying relevant studies	- Keogh et al (14) list of included studies selected as a source of relevant studies. - Other recent publications identified myself via websites and personal communication with experts
Stage 3	Study selection	- Selection criteria applied to abstracts and full texts if needed
Stage 4	Charting the data	- Data extracted and tabulated about main characteristics of studies and data from each about uptake, acceptance or rejection of interventions
Stage 5	Collating, summarizing and reporting the results	- Common categories of influences and overall themes identified

Appendix 2.4 Keogh et al's (14) **scoping literature review criteria**

Inclusion criteria	Exclusion criteria
- Primary research and evidence reviews - Interventions designed for people with a confirmed diagnosis of mild/ - moderate dementia, - Interventions designed for the person alone or with a nominated informal carer - Only involved people living in the community in their own homes - Published in English and from 2000 onwards	- Case study reports, study protocols, conference abstracts and non-research publications - Did not involve people with a diagnosis of mild/moderate dementia - Interventions designed primarily for people with other health conditions who also have cognitive loss - Involved people living in residential care, or other institutional settings - Interventions for family carers only - Interventions for staff

Appendix 2.5 Summary of main characteristics for studies included in the review of recent evidence (n=28)

	Author (date) country (thesis reference list number)	Study design and main objective	Study populations[1]	How severity of dementia or cognitive impairment assessed or reported	Intervention name and/or description
	Studies identified from Keogh et al's (14) **scoping review**				
1	Gitlin et al (2018) USA (99)	Single-blind parallel, RCT compared intervention to a control group to determine whether intervention reduce behavioural symptoms and functional dependence of veterans with dementia and caregiver burden	160 Veterans with dementia and family caregivers, community living, able to participate in 2 or more self-care activities *[type of dementia not reported]*	MMSE 23 or below; MMSE mean of 16.6 (says +/- 7.8, range 0–29). *[Inferred majority moderate]*	Tailored Activities programme: up to 8 in-home sessions delivered by occupational therapists. Activity prescriptions detail activity goals, how to set up the environment and strategies for implementation. Graded activities drew upon preserved abilities and reduced task demands, enabling engagement by minimizing distress, sensory overload and compensating for executive dysfunctions. Demonstration for caregivers to use activities, manage situational distress, and understand behavioural symptoms.
2	Quinn et al (2016) Wales (117)	Pilot RCT explored feasibility of intervention to improve self-efficacy compared to treatment as usual	24 participants with early-stage dementia and a caregiver *[ICD-10 diagnostic criteria cited, inferring any dementia type included]* *[Community – dwelling inferred as reported researchers visited participants at home]*	Early-stage dementia, indicated by a MMSE score of 20 or above	Self-management: Eight weekly 90-minute group sessions. Participants asked to name the group. Each session had a consistent structure. Within each topic, participants select the most pertinent aspects to discuss and were encouraged to problem-solve and set goals. Each session finished with a mindfulness based exercise. Caregivers were invited to attend first and final sessions and could join the end of each meeting.

	Author (date) country (thesis reference list number)	Study design and main objective	Study populations[1]	How severity of dementia or cognitive impairment assessed or reported	Intervention name and/or description
3	Woods et al (2016) England and Wales (110)	Pragmatic parallel group eight-centre RCT assessed effectiveness and cost-effectiveness of intervention compared to usual care	488 community living participants with mild to moderate dementia and a family carer [ICD-10 diagnostic criteria cited; inferring any type of dementia included]	Able to communicate and understand communication, to some degree (score of 1 or 0 on specific items of the Clifton Assessment Procedures for the Elderly Behaviour Rating Scale) and able to engage in group activity	Joint group reminiscence therapy for person with dementia and carer. Manualised intervention developed for this study. Joint reminiscence groups emphasised active and passive reminiscence by carers and people with dementia. Weekly over 12 consecutive weeks, followed by seven monthly maintenance group sessions. Sessions led by two trained facilitators, supported by trained volunteers.
4	Cheston and Howells (2016) England (106)	Descriptive report of intervention	5 participants dementia diagnosis (excluding Frontal-Temporal dementia) within the previous 18 months, and their carers. *[Community living inferred as recruited from primary care teams and local Memory clinic] [type of dementia not reported]*	Person acknowledged at least occasionally, a memory problem, had adequate communication skills for group participation and a mild or moderate level of cognitive impairment	"Living Well with Dementia" (LivDem) model of group support for people affected by dementia within a Primary Care setting: 10 week group, joint sessions with carer held on the first and the final meetings, with separate parallel group sessions for people affected by dementia and their carers for the remaining eight sessions.

	Author (date) country (thesis reference list number)	Study design and main objective	Study populations[1]	How severity of dementia or cognitive impairment assessed or reported	Intervention name and/or description
5	Sobol et al (2016) Denmark (111)	Multicentre single-blinded RCT assessed effects of intervention on cognition, health-related quality of life, activities of daily living, behavioural and psychological symptoms compared to usual care	200 community dwelling participants with AD and caregivers in contact with the participant at least once monthly	MMSE ≥ 20	Physical exercise: 1 hour, 3 times weekly for 16 weeks in groups of 2–5 participants supervised by a qualified physical therapist. First 4 weeks focused on adaptation to exercising, strength training of the lower extremity muscles, introduction to aerobic exercise. The following 12 weeks included moderate-to-high–intensity aerobic exercise on ergometer bicycle, cross trainer, treadmill in 3 periods of 10 minutes with 2–5 minutes pause in-between. The aerobic exercise was individually tailored and planned.
6	Holthoff et al (2015) Germany (114)	Pilot RCT assessed effect of intervention compared to usual care on clinical symptoms, functional abilities, carer burden	30 community living participants with AD and their family caregivers	MMSE mean: 20.6 ±6.5 points	Home-based physical activity programme for 12 weeks: passive, motor-assisted and active resistive leg training and changes in direction on a movement trainer in order to combine physical and cognitive stimuli.
7	Marshall et al (2015) England (107)	Pilot RCT assessed recruitment rates, acceptability of intervention, training procedures, variance of outcomes, loss to follow-up	58 community living individuals with AD	Acknowledged, at least occasionally, that they have a memory problem; MMSE at least 18	'Living well with Dementia (LivDem) group intervention; 10 weekly sessions delivered by nurses from a memory clinic.
8	Orgeta et al (2015) England and Wales (109)	Multicentre, pragmatic RCT evaluated clinical and cost-effectiveness of intervention on quality of life for people with dementia and mental and physical health for carers with treatment as usual	356 community living caregiving dyads were recruited (273 completed the trial) with AD, VD, Lewy body type or mixed	MMSE 10 or above	Individual cognitive stimulation therapy (iCST): iCST consisted of structured cognitive stimulation sessions for people with dementia, completed up to three times weekly over 25 weeks. Family carers were supported to deliver the sessions at home.

	Author (date) country (thesis reference list number)	Study design and main objective	Study populations[1]	How severity of dementia or cognitive impairment assessed or reported	Intervention name and/or description
9	Sprange et al (2015) England (103)	Pilot study to determine feasibility of a trial into a self- management intervention	7 community-living participants with early-stage dementia (5 family carers also participated) [type of dementia not reported]	MMSE 20 or above; NHS partners also used clinical judgement when identifying potential participants	Self-management: 'Journeying through Dementia': 12-week manualised participant-directed group programme with 4 individual sessions with a facilitator to pursue personal goals; group meets weekly for approx.2 hrs, community venue. Participants facilitated to choose topics of relevance from a menu.
10	Kanaan et al (2014) USA (96)	Pre and post-test study test the feasibility and efficacy of intervention (no control) group	21 participants with mild or very mild AD [community living inferred; participants had to travel to the medical centre]	Clinical Dementia Rating (CDR) scale 0.5-1	Cognitive training:; intensive practice for 10 days over 2 weeks, 4 to 5 hours of training each day involving computer-based tasks for attention and working memory
11	Galvin et al (2014) USA (100)	Non-randomised multisite evaluation compared intervention to test whether early dementia detection and comprehensive care consultations improve carer burden, care confidence, and mood in person with dementia, and effect on delaying transitions in level of care, with control (Alzheimer's Association usual services)	244 community-dwelling older adults screened for early-stage dementia [type of dementia not reported]	'AD8' dementia screening tool, scoring ≥2	Collaborative project between Missouri Department of Health, Area Agencies on Aging (AAA), Alzheimer Association, and academic researchers: AAA Care Coordinators conducted an assessment, including the 'AD8' dementia screen. If a client scored 2 points or higher on the AD8, the care coordinator suggested to client (or family member) a referral to the Alzheimer Association. An individualized 'Project Learn More' consultation with the Alzheimer's Association offered to the referred individuals. The services rendered by the AAA and Alzheimer Association constituted the standard of care practices for each agency.

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	Author (date) country (thesis reference list number)	Study design and main objective	Study populations[1]	How severity of dementia or cognitive impairment assessed or reported	Intervention name and/or description
12	Milders et al (2013) Scotland (116)	Pre-post-test study investigated: whether caregivers were able to present the exercises as intended; effect of intervention on well-being of caregivers and people with dementia	29 community living participants with mild to moderate dementia, and their main caregiver *[ICD-10 diagnostic criteria cited, inferring any dementia type included]*	MMSE mean of 19.1	Cognitive stimulation: intervention involved the caregiver engaging their relative in stimulating activities. A manual for caregivers described 48 activities and guidelines on how to present them. A calendar also provided.
13	Canonici et al (2012) Brazil (118)	Controlled trial examined benefits of a motor intervention for functional dependence and caregiver burden.	32 community living participants with mild to moderate AD and their 32 caregivers.	CDR 1 or 2	A motor intervention programme: 60 minutes of exercises, 3 times per week over 6-months to improve flexibility, strength, agility and balance. Caregivers followed the procedures with the person with dementia.
14	Vreugdenhil et al (2012) Australia (119)	RCT compared effects of intervention to usual care on cognitive and physical function and activities of daily living	40 community dwelling participants with AD and their informal carers	MMSE mean 22.9/30 (range 13-28) for intervention group and 21/30 (range 10-28) for controls	Physical exercise: 10 exercises daily for 4 months, each with three progressively challenging levels, focusing on upper and lower body strength and balance training in addition to at least 30 minutes of brisk walking supervised by their carer.

	Author (date) country (thesis reference list number)	Study design and main objective	Study populations[1]	How severity of dementia or cognitive impairment assessed or reported	Intervention name and/or description
15	Waldorff et al (2012) Denmark (112)	RCT assessed efficacy at 12 months of an early psychosocial counselling and support programme	330 participants (community living) with mild AD and primary care givers (50 years+ mean age for people with dementia 76.2, inferred majority 65+)	MMSE 20 or above	Danish Alzheimer's Intervention Study (DAISY) intervention: multifaceted semi-tailored counselling, education and support over 8-12 months. Included: up to 7 counselling sessions (2 for dyad, 2 for the participant, 2 for care giver and optional network session with participant, care giver and family network); Education - 5 sessions, parallel groups for participants and carers about disease and its consequences whilst establishing a forum for exchange of experiences and coping strategies.
16	Voigt-Radloff et al (2011) Germany (113)	Seven-centre, parallel group RCT compared effect of intervention on people with dementia's daily functioning intervention to control	141 'dyads' (participants with AD living in the community with primary carer available)	MMSE 14–24	10-session Community Occupational Therapy programme over 5 weeks (based on Dutch COTiD intervention described above (Graff et al, 2006)
17	Clare et al (2010) England & Wales (108)	Single blind RCT compared effectiveness of intervention on goal performance and satisfaction with relaxation therapy and no treatment	69 community living participants with Alzheimer's Disease (AD), mixed AD & Vascular Dementia (VD); 44 family carers	Mini-Mental State Examination (MMSE) 18 or above	Cognitive rehabilitation (CR): 8 weekly sessions of personalized interventions to address individually relevant goals
18	Neely et al (2009) Sweden (115)	RCT examined effectiveness of intervention compared to person with dementia receiving same training without the caregiver and a control group (couples receiving no training)	30 community living participants with mild to moderate AD or VD within eight months prior to intervention and a carer living with them	Records that people with dementia had difficulty remembering things and performing daily activities	Collaborative memory intervention: the couple acquired and practised memory supportive strategies (spaced-retrieval and hierarchical cuing) to learn a face–name association and to set a table for coffee/tea.

	Author (date) country (thesis reference list number)	Study design and main objective	Study populations[1]	How severity of dementia or cognitive impairment assessed or reported	Intervention name and/or description
19	Burgener et al (2008) USA (102)	RCT tested the effectiveness of intervention on cognitive functioning, physical functioning and behavioural outcomes compared to control	43 participants with AD, Lewy body, VD, frontal lobe, or mixed dementia *[Community living inferred as had to travel to intervention]*	CDR score of <2	Multimodal 40 week intervention involved Taiji exercises, cognitive-behavioural therapies and a support group.
20	Miu et al (2008) Hong Kong (121)	RCT studied the effect of intervention on physical function, cognition, affect and carer stress compared to a control group	85 community living participants with AD, VD or other dementia; carers who can participate and escort	Cantonese version MMSE 10-26	Physical exercise: intervention involved a group receiving aerobic exercise training with treadmill, bicycle, arm ergometry and flexibility exercises carried out for 1 hour twice a week for 12 weeks, at a medical centre.
21	Graff et al (2006) Netherlands (19)	Single blind RCT determined effectiveness of intervention on daily functioning of people with dementia and the sense of competence of their care givers.	135 'dyads' (participants with dementia living in the community and their primary carer who cared for them at least once a week) *[type of dementia not reported]*	Brief cognitive rating scale with (scores of 9-24 indicating mild dementia, 25-40 indicating moderate dementia)	Community Occupational therapy in Dementia (COTiD): 10 sessions of occupational therapy over 5 weeks including cognitive and behavioural interventions to train participants to compensate for cognitive decline and care givers in coping behaviours and supervision.
22	Burns et al (2005) England (104)	RCT assessed whether psychotherapeutic intervention could benefit cognitive function, affective symptoms and global well-being versus usual care	40 (20 control group, 20 intervention group) community living. Individuals with AD and carer in regular contact	CDR 1 and MMSE 15 or above	Brief psychotherapy: 6 sessions of psychodynamic interpersonal therapy for the person with dementia with an experienced psychotherapist (carers participated in baseline and outcome measures).

	Author (date) country (thesis reference list number)	Study design and main objective	Study populations[1]	How severity of dementia or cognitive impairment assessed or reported	Intervention name and/or description
23	Cheston et al (2003) England (105)	Pre-post-test study assessed impact of intervention groups on participants' medication use and levels of anxiety and depression	Community living participants with AD or another form of dementia, 42 participants entered the project at different points, of whom 19 completed the baseline, intervention and follow-up phases	Person acknowledged, at least occasionally, a memory problem and that this was more than just the effects of old age; that s/he was willing to attend a support group; MMSE of at least 18	Group psychotherapy:10 sessions mostly in community venues; led by an experienced psychotherapist with co-facilitator/s. Participants asked to discuss 'what it's like when your memory isn't as good as it used to be'. Participants encouraged to share experiences with each other and discuss the emotional impact of these experiences. The facilitator's role was to reflect upon the emotional significance of these experiences within the group context.
24	Fitzsimmons and Buettner (2003) USA (98)	Pilot study examined is it possible to develop an educational method that enables individuals with early-stage dementia to learn new information, change health behaviours and impact depression, self-esteem, self-efficacy and stress.	10 community living participants with dementia (one lived in assisted living facility) *[type of dementia not reported]*	MMSE mean of 21.7	Experimental college course for those newly diagnosed; focus on promoting and maintaining optimal health; weekly 2 hour class for 10 weeks. Spouses and caregivers not allowed to stay in the classroom during the course.
25	Goldsilver and Gruneir (2001) Canada (120)	Evaluation of service offering support groups to help individuals connect to one another, gain understanding and develop coping techniques	31 participants with early stage dementia ('diagnosis of AD or dementia') *[Community living inferred as recruited*	MMSE 18-30	Support group: 8 weekly meetings for 1.25 hours facilitated by a social worker and occupational therapist; Topics for discussion suggested by facilitators chosen for their interest and educational value. Examples included the brain and behaviour, energy conservation, reminiscence, coping with loss, and strategies to improve memory.

	Author (date) country (thesis reference list number)	Study design and main objective	Study populations[1]	How severity of dementia or cognitive impairment assessed or reported	Intervention name and/or description
			via different community based organisations and services]		
26	Moore et al (2001) USA (97)	Case control study examined efficacy of intervention compared to controls	25 participants with mild to moderate AD and their caregivers *[community living inferred as recruited from outpatient clinics/ community service]*	Severity assessed by consensus of the clinical team	Memory training: 5 weeks with a 1 month follow up including name and face rehearsal, effortful recall and a significant event technique. All of the memory training exercises required interaction between the patient, caregiver and instructor
	Additional papers identified				
27	Clare et al (2019) (20) England & Wales	Parallel group, multi centre single blind RCT determined whether intervention (added to usual care) improved everyday functioning for people with mild-moderate dementia compared to usual care	Community living participants with AD, VD or mixed dementia and a family member willing to contribute	MMSE 18 or above	Cognitive rehabilitation (CR): participants allocated to CR received 10 weekly sessions over 3 months and 4 maintenance home based sessions over 6 months. Participants worked collaboratively with a therapist on up to three rehabilitation goals chosen by participants using a problem solving approach.
28	Field et al (2019) (34) England	Secondary qualitative analysis of existing semi-structured post-intervention interviews exploring influences on uptake of the intervention	17 community living participants with AD, VD or mixed type mild to moderate dementia and a family member	CDR score of 0.5-2	Community occupational therapy offered as part of development phase for the UK 'VALID' research programme, adapted from a Dutch intervention (19). Approximately 10 tailored sessions for person with dementia and family member, with an occupational therapist in people's homes or communities. Intervention aimed to promote independence, meaningful activity and quality of life.

Abbreviations: **AD** Alzheimer's Disease **CDR** Clinical Dementia Rating Scale (123)[2] **CR** Cognitive Rehabilitation **ICD-10** International Classification of Diseases 10 **MMSE** Mini Mental State Exam (122)[2] **RCT** Randomised Control Trial **VD** Vascular Dementia [1]Criteria for study populations: individuals reported as having a diagnosis of a dementia, being in the early or mild to moderate stages and community living. Exclusions: day care attendees or mixed samples (e.g. mild to moderate dementia with severe dementia, or community living people combined with day care attendees and/or those in residential living, if results are not presented separately). [2]Studies included on this table may have cited different references for these assessments, I have chosen to cite these as sources for ease of reference

Appendix 2.6 Information about uptake summarised and themes identified

Information identified [no. of studies reporting this type of data] (thesis reference numbers)	Examples of information identified (thesis reference numbers)	Themes identified to inform model of readiness to engage in psychosocial interventions, by people with early dementia
Recruitment difficulties [5 studies] (100,103,107,120,121)	Other health priorities (100)	Comorbidities , personal, social or living circumstances
	Intervention not required (no further explanation) (100) Referrals not reflecting ethnic diversity of location (120)	Intervention characteristics: perceived as not potentially meeting needs
	Staff consider overall physical and mental health before approaching potential participants in addition to study screening criteria (107) 24-28hr telephone contact immediately after study information received facilitates recruitment (103) Coordinating community service partners to generate referrals and ensuring screening protocols are followed by staff to identify appropriate people recommended (100) Active involvement of facilitators, outreach, promotion, face-to-face assessment recommended as this population don't tend to come forward on own initiative (120)	Services and staff role: how information is offered by services; staff role in assessing suitability for intervention
	Limited availability of working carers (121)	Key role of family members: limited availability
Exclusion or declining to participate [18 studies] (19,20,110–112,114–117,119,120,99,103–109)	Moving/relocation (including to residential care) (107,109,110,116) Assisted living setting (99) Time constraints (20,110,115,119) Family situation (110) Death of either person (109) Health issues for either person (109,110,119) Travel/holiday plans (114,120)	Comorbidities, personal, social or living circumstances
	No suitable carer to participate in a dyad intervention (99,110,115) Limited availability of working carers (121)	Key role of family members: needed for dyad interventions

Information identified [no. of studies reporting this type of data] (thesis reference numbers)	Examples of information identified (thesis reference numbers)	Themes identified to inform model of readiness to engage in psychosocial interventions, by people with early dementia
	Inclusion criteria not met or potentially eligible people declined (no further explanation) (19,20,116,100,102,106–108,110–112) Diagnostic criteria not met (99,107,117) Person with dementia 'unaware of diagnosis', denial/lack of insight, does not like groups (110)	Dementia related characteristics
	Prefers group activity/doing own activities at home/intervention not suitable, became distressed during interview, family do not discuss diagnosis (109) Reluctant to meet others with dementia (107) Potential for sessions to upset person with dementia (104) Exercise did not appeal to either person (119) Content with current situation (20)	Intervention characteristics: not perceived as potentially meeting needs or preferences
Limited engagement in interventions (i.e. reasons for drop-out or non-attendance) [15 studies] (98,99,116–118,121,102,103,105–107,110,112,113)	Ill health of either person including hospital admissions (19,98,118,102,103,105–107,112,113,117) Visiting family (102) Death of either person (19,105,109,112,121) Participating in other interventions/studies (19,102) Relocation/move to residential care (19,98,102,109,116,117) Refusal to participate/consent withdrawn (no further explanation) (19,99,116,121)	Comorbidities, personal, social or living circumstances
	Assessments too stressful for person with dementia (or carer), carer found it difficult/stressful to motivate person with dementia (116)	Intervention characteristics: not perceived as potentially meeting needs or preferences
	Carer stress or ability to collaborate (113,116)	Key role of family members: carer stress and collaboration
	Person with dementia's cooperation, daily changing mental capacity and acceptance of adaptations/suggestions (113)	Dementia related characteristics
Expectations of or	Intervention acceptable because it fostered independence, social	Intervention characteristics: perceived as

Information identified [no. of studies reporting this type of data] (thesis reference numbers)	Examples of information identified (thesis reference numbers)	Themes identified to inform model of readiness to engage in psychosocial interventions, by people with early dementia
acceptability of interventions and influences on uptake [4 studies] (34,103,109,117)	support and provided clinician facilitator support (117) Intervention regarded as opportunity to support independence, carers were supportive of this aim (34,103) Intervention offered opportunity for enjoyable/ meaningful activities (34,109)	potentially meeting needs
	Carers felt intervention supported better understanding of the person with dementia's needs (109)	Key role of family members: encouraging uptake
	Memory capacity regarded as indicator of ability to benefit from intervention and potential benefit (103) Impact of dementia and wanting support (34)	Dementia related characteristics: memory capacity as indicator of potential benefit and suitability of intervention
Discussion of results [9 studies] (96–98,100,105,108–110,113)	Higher cognitive ability may lead to more successful outcomes (108) Limited need for assistance initially may partly explain why no beneficial effect found for intervention (113) Participant had capacity and willingness to talk about themselves and their memory problems, some did not want to, not representative of wider population with dementia, notes those without cognitive problems may not want to join psychotherapy groups (105) Motivation of person with dementia affects engagement in intervention (97) Motivation and fatigue did not prohibit engagement in intervention despite concerns (96) Recall between sessions or forgetting to attend sessions not an issue, despite concerns (98) Readiness to make changes and motivation to address goals important for practitioners at initial assessment (20)	Dementia related characteristics: cognitive level, motivation, fatigue, need for assistance, awareness/insight, readiness to make changes

Information identified [no. of studies reporting this type of data] (thesis reference numbers)	Examples of information identified (thesis reference numbers)	Themes identified to inform model of readiness to engage in psychosocial interventions, by people with early dementia
	Some carers expressed discomfort with the intervention, examples of people with dementia enjoying the groups but being withdrawn by carers who were less enthusiastic (110) Reducing responsibility on family care givers may facilitate gain from or engagement in intervention (109)	Key role of family member: may not facilitate uptake or engagement; carer stress

Appendices for Chapter 3

Appendix 3.1 Research Ethics Committee Approval Letter

NHS
Health Research Authority

North West - Greater Manchester East Research Ethics Committee

<div align="right">
3rd Floor, Barlow House
4 Minshull Street
Manchester
M1 3DZ
Telephone: 020 71048008
</div>

05 September 2017
Dr Elizabeth Coates
Research Associate / Academic Supervisor
University of Sheffield
School of Health and Related Research (ScHARR)
Regent Court, 30 Regent St, Sheffield
S1 4DA

Dear Dr Coates

Study title:	**A study to explore how people with early stage dementia respond to offers of psychosocial interventions and whether a readiness to engage in psychosocial interventions can be identified.**
REC reference:	**17/NW/0414**
IRAS project ID:	**227380**

Thank you for responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair and Mr Benn.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk 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 management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the 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).

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).

Approved documents
The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date

Copies of advertisement materials for research participants [Flyer v1 10.05.2017 B Field IRAS 227380]	v1	10 May 2017
Covering letter on headed paper [Recruitment cover letter v1 10.05.2017 B Field IRAS 227380]	v1	10 May 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [To Whom It May Concern 2016]	1	15 November 2016
Interview schedules or topic guides for participants [Topic guide pwd or dyads v1 10.05.2017 B Field IRAS 227380]	v1	10 May 2017
Interview schedules or topic guides for participants [Indicative brief topic guide managers v1 10.05.2017 B Field IRAS 227380]	v1	10 May 2017
Interview schedules or topic guides for participants [Indicative topic guide staff v1 10.05.2017 B Field IRAS 227380]	v1	10 May 2017
IRAS Application Form [IRAS_Form_16062017]		16 June 2017
Letters of invitation to participant [Invite staff v1 10.05.2017 B Field IRAS 227380]	v1	10 May 2017
Non-validated questionnaire [Demographic questionnaire v1 10.05.2017 B Field IRAS 227380]	v1	10 May 2017
Other [Appointment letter v1 10.05.2017 B Field IRAS 227380]	v1	10 May 2017
Other [Calling Card v1 10.05.2017 B Field IRAS 227380]	v1	10 May 2017
Other [Capacity assessment v1 10.05.2017 B Field IRAS 227380]	v1	10 May 2017
Other [Info about VALID research programme B Field IRAS 227380]	v1	10 May 2017
Other [no contact letter v1 10.05.2017 B Field IRAS 227380]	v1	10 May 2017
Other [thank you letter v1 10.05.2017 B Field IRAS 227380]	v1	10 May 2017
Other [Validation invite v1 05.06.2017 B Field IRAS 227380]	v1	05 June 2017
Other [thank you validation v1 10.05.2017 B Field IRAS 227380]	v1	10 May 2017
Other [certificate of insurance]	1	15 June 2017
Other [Permission to contact slip]	2	30 August 2017
Participant consent form [consent form pwd v1 10.05.2017 B Field IRAS 227380]	v2	01 August 2017
Participant consent form [consent form fc v1 10.05.2017 B Field IRAS 227380]	v2	01 August 2017
Participant consent form [Consent form staff v1 10.05.2017 B Field IRAS 227380]	v2	01 August 2017
Participant consent form [verbal consent form managers v1 10.05.2017 B Field IRAS 227380]	v2	01 August 2017
Participant information sheet (PIS) [Participant information dyads v1 10.05.2017 B Field IRAS 227380]	v2	01 August 2017
Participant information sheet (PIS) [Participant information pwd v1 10.05.2017 B Field IRAS 227380]	v2	01 August 2017
Participant information sheet (PIS) [Participant Information staff v1 10.05.2017 B Field IRAS 227380]	v2	01 August 2017
Participant information sheet (PIS) [amended_staff_clean]	v3	09 August 2017
Research protocol or project proposal [Becky Field Protocol v1 06.06.2017]	v2	20 July 2017
Summary CV for Chief Investigator (CI) [CV Elizabeth Coates 17.03.17]	v1	17 March 2017
Summary CV for student [Becky Field IRAS CV 25.04.2017]	v1	25 April 2017

Summary CV for supervisor (student research) [G Mountain IRAS CV 24.04.2017]	v1	24 April 2017
Summary CV for supervisor (student research) [CV Elizabeth Coates 17.03.17]	v1	17 March 2017
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Lay Summary JDR v1 10.05.2017 B Field IRAS 227380]	v1	10 May 2017
Summary, synopsis or diagram (flowchart) of protocol in non technical language [One page summary v1 10.05.2017 B Field IRAS 227380]	v1	10 May 2017

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 HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-thehra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

17/NW/0414   **Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

Dr Simon Jones Chair
Email:nrescommittee.northwest-gmeast@nhs.net

Enclosures: "After ethical review – guidance for
                   researchers"

Copy to: *Ms Becky Field*
                  *Ms Helen Oldknow, Rotherham, Doncaster and South Humber NHS
                  Foundation Trust*

NHS patient ID/NHS trust ID:………………………………………

<div style="border:1px solid black; text-align:center;">

Permission to contact slip

</div>

Take up of support and services after diagnosis: research project

I give permission for these contact details to be passed to Becky Field (University of Sheffield). This is so that she can contact me, to ask if I'd like to talk to her about my views and experiences. I am under no obligation to take part.

Name:………………………………………………………………………………
…………………………………………

Address:……………………………………………………………………………
……………………………….......

Telephone number:

Email (if appropriate):

Signed…………………………………………………………
Date……………………………………………………….

The
University
Of
Sheffield.

Information for participants – people with dementia

Research project title: A study to explore how people with early stage dementia respond to offers of support and services.

You have been invited to take part in a research project. 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. Please ask me if there is anything that is unclear or if you would like more information. Take time to decide whether or not you wish to take part. Please feel free to discuss this with other people.

Thank you for reading this.

What is the purpose of the research?

This research is exploring how people with dementia respond to offers of support or services provided by the NHS.

We want to understand more about how people with dementia respond to offers of support or services after diagnosis, focusing on services other than those to do with medication or drugs. This is because health policy promotes support for people after diagnosis. Also research evidence suggests that people with dementia and their carers can benefit from services aimed to support them, for example when interventions are aimed at improving thinking skills such as memory, daily living skills or quality of life. However, such NHS services for people with dementia are still developing.

I am doing this project as part of a PhD at the University of Sheffield.

Why have I been chosen?

You were suggested for this for this research either because you use NHS memory services or expressed an interest on the 'Join Dementia Research' online register (https://www.joindementiaresearch.nihr.ac.uk)

To participate you need to have a diagnosis of dementia - given within the last two years or so - and to be living at home, or in sheltered accommodation, and living with the early stages of dementia.

You will be one of 10-30 individuals taking part in this project. NHS staff will also be asked to take part in this study.

Do I have to take part?

It is up to you to decide whether or not to take part in this research. You can withdraw at any time without giving a reason. Whether or not you take part will not affect any services you receive.

What will happen to me if I take part?

1) I will talk to you about what taking part involves.
2) If you are interested in taking part, I will ask you, or someone else if you wish (for example, a spouse, relative or friend) a few background questions, for example, about when you were given a diagnosis of dementia, the type of dementia you have been diagnosed with, your age and current health. This is to help us work out if this research project is suitable for you. I can ask these questions over the telephone, or send a short questionnaire in the post with a stamp addressed envelope, or I can ask you the questions in person. You can ask someone who knows you to help you complete the short questionnaire, or complete it on your behalf, example a friend, relative, health or social care worker.
3) If this research project is suitable for you and you wish to talk part, **I will invite you to take part in one face to face to interview.** We will arrange this at time that is convenient for you. This can be at your home or a room at the University if you prefer.
4) I will ask you to sign a consent form before the interview begins.
5) The interview may last up to one hour but can be shorter.
6) You will be given a copy of this information sheet to keep and if you decide to take part, a copy of the signed consent form.

I would like to audio-record the interview.

If you give your consent to be contacted again in the future, I may contact you again towards the end of the project to ask if you would like to comment on the main findings. Also, if you would like a copy of the main findings, I will send these to you when the project is complete.

What are the possible disadvantages and benefits of taking part?

It is not anticipated that you will be disadvantaged by taking part in this research. During the interview there is a chance that you may feel tired or upset. We can stop the interview at any time and take a break, re-schedule, or cancel it all together. You can withdraw at any time without giving a reason.

Whilst there are no immediate benefits from taking part, it is hoped that you may enjoy being interviewed and sharing your views and experiences.

What if something goes wrong?

If you wish to make a complaint about this research please contact the project supervisors: Professor Gail Mountain g.a.mountain@sheffield.ac.uk or Dr Elizabeth Coates, e.coates@sheffield.ac.uk University of Sheffield, ScHARR, Telephone 0114 222 0886 or Dean of ScHARR, Professor John Brazier, University of Sheffield Regent Court, 30 Regent Street, Sheffield, S1 4DA telephone (0114 222 5446 - Dean's Office)

Will my taking part in this project be kept confidential?

The information that I collect from you during the course of the research will be treated in confidence. It will not be possible to identify you in any reports or publications.

Will I be recorded, and how will the recorded media be used?

Audio recordings of the interview will be made, and then transcribed (typed up). This is to make sure that an accurate record of the interview is made to be used in analysis. If you do not wish for the interview to be recorded, we can still go ahead but I will need to make some notes as we talk.

Who will have access to the data and where will it be held?

All data, including audio recordings and transcripts of interviews will be treated confidentially, and held on secure computer drives and password protected computers at the University of Sheffield. Transcripts of the interview will be anonymised, so that your name or any other identifying details will be removed from the interview transcript. Audio recordings of interviews will be stored securely on a password protected computers at the University of Sheffield until the project is completed and then they will be destroyed. Only the project team and a professional transcriber will have access to the data. Any professional transcriber employed will have completed information governance and data protection training required by the University of Sheffield. Paper copies of transcripts will be kept in a locked filing cabinet. Also, your contact details will be stored securely on a password protected computer at the University of Sheffield until the project is complete and then destroyed. Consent forms

and anonymised interview transcripts will be kept for five years after completion of the project, and then destroyed.

What will happen to the results of the research project?

The findings will be presented nationally and internationally at academic conferences, to NHS organisations and submitted for publication in academic journals. The aim of this will be to inform NHS practice and service developments for people with dementia. Participants in the study will not be identifiable in any of the reported material.

A summary of findings will be shared with you if you request this.

A full report will be included in a thesis submitted for examination as part of a PhD. This is due for completion in 2020. This will be available online via http://etheses.whiterose.ac.uk/

Who is organising and funding the research?

This research has partly been funded by the National Institute of Health Research, as this organisation funded another research study called 'Valuing Active Life in Dementia' (VALID), for which I worked as a paid member of research staff. That work led my undertaking this PhD research project, partly while a paid member of research staff.

Who has ethically reviewed the project?

This project has been reviewed and approved by North West Greater Manchester East Research Ethics Committee (Reference Number: 17/NW/0414), the Health Regulation Authority, Rotherham Doncaster and South Humber NHS Foundation Trust and Sheffield Health and Social Care Foundation NHS Trust.

Please contact me if you have any questions about this research.

Becky Field

Telephone: 0114 222 2985 Email: b.field@sheffield.ac.uk

Address: School of Health & Related Research (ScHARR)
University of Sheffield, Regent Court, 30 Regent Street,
Sheffield S1 4DA

THANK YOU FOR TAKING THE TIME TO CONSIDER THIS RESEARCH

The
University
Of
Sheffield.

Information for participants – people with dementia and their family carers or supporters

Research project title: A study to explore how people with early stage dementia respond to offers of support and services.

You both have been invited to take part in a research project. 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. Please ask me if there is anything that is unclear or if you would like more information. Take time to decide whether or not you both wish to take part. Please feel free to discuss this with other people.

Thank you for reading this.

What is the purpose of the research?

This research is exploring how people with dementia respond to offers of support or services provided by the NHS.

We want to understand more about how people with dementia respond to offers of support or services after diagnosis, focusing on services other than those to do with medication or drugs. This is because health policy promotes support for people after diagnosis. Also research evidence suggests that people with dementia and their supporters or carers can benefit from services aimed to support them, for example when interventions are aimed at improving thinking skills such as memory, daily living skills or quality of life. However, such NHS services for people with dementia are still developing.

I am doing this project as part of a PhD at the University of Sheffield.

Why have you been chosen?

The person with dementia was suggested for this for this research either because they use NHS memory services or one of you expressed an interest on the 'Join Dementia Research' online register (http://www.joindementiaresearch.nihr.ac.uk). The person with dementia has also said they would prefer to be interviewed with another person of their choosing.

To participate, the person with dementia needs to have a diagnosis of dementia - given within the last two years or so. They also need to be living at home, or in sheltered accommodation, and living with the early stages of dementia.

You both need to be able and willing to take part in a face to face interview, together.

You will be one of 10-30 individuals taking part in this project. NHS staff will also be asked to take part in this study.

Do I have to take part?

It is up to you both to decide whether or not to take part in this research. You can withdraw at any time without giving a reason. Whether or not you take part will not affect any services you receive.

What will happen to me if I take part?

1) I will talk to you both about what taking part involves.
2) If you are both interested in taking part, I will ask one or both of you a few background questions, for example, about when the diagnosis of dementia was given, the type of dementia diagnosed, age and current health. This is to help us work out if this research project is suitable for you both. I can ask these questions over the telephone, or send a short questionnaire in the post with a stamp addressed envelope, or I can complete it with either of you in person.
3) If this research project is suitable for you both and you both wish to talk part, **I will invite you to take part in one face to face to interview together.** We will arrange this at time that is convenient for you. This can be at your home or a room at the University if you prefer.
4) I will ask you both to sign a consent form before the interview begins. The interview may last up to one hour but can be shorter.
5) You will be given a copy of this information sheet to keep and if you decide to take part, a copy of the signed consent form.

I would like to audio-record the interview.

If either of you give your consent to be contacted again in the future, I may contact you again towards the end of the project to ask if you would like to comment on the main findings. Also, if you would like a copy of the main findings, I will send these to you when the project is complete.

What are the possible disadvantages and benefits of taking part?

It is not anticipated that you will be disadvantaged by taking part in this research. During the interview there is a chance that either of you may feel tired or upset. We can stop the interview at any time and take a break, re-schedule, or cancel it all together. You can both withdraw at any time without giving a reason.

Whilst there are no immediate benefits from taking part, it is hoped that you both may enjoy being interviewed and sharing your views and experiences.

What if something goes wrong?

If you wish to make a complaint about this research please contact the project supervisors: Professor Gail Mountain g.a.mountain@sheffield.ac.uk or Dr Elizabeth Coates, e.coates@sheffield.ac.uk University of Sheffield, ScHARR, Telephone 0114 222 0886 or Dean of ScHARR, Professor John Brazier, University of Sheffield Regent Court, 30 Regent Street, Sheffield, S1 4DA telephone (0114 222 5446 - Dean's Office)

Will our taking part in this project be kept confidential?

The information that I collect from you during the course of the research will be treated in confidence. It will not be possible to identify you in any reports or publications.

Will I be recorded, and how will the recorded media be used?

Audio recordings of the interview will be made, and then transcribed (typed up). This is to make sure an accurate record of the interview is made to be used in analysis. If you do not wish for the interview to be recorded, we can still go ahead but I will need to make some notes as we talk.

Who will have access to the data and where will it be held?

All data, including audio recordings and transcripts of interviews, will be treated confidentially, and held on secure computer drives and password protected computers at the University of Sheffield. Transcripts of the interview will be anonymised, so that your name or any other identifying details will be removed from the interview transcript. Audio recordings of interviews will be stored securely on a password protected computers at the University of Sheffield until the project is completed and then they will be destroyed. Only the project team and a professional transcriber will have access to the data. Any professional transcriber employed will have completed information governance and data protection training required by the University of Sheffield. Paper copies of transcripts will be kept in a locked filing cabinet. Also, your contact details will be stored securely on a password protected computer at the University of Sheffield until the project is complete and then destroyed. Consent forms

and anonymised interview transcripts will be kept for five years after completion of the project, and then destroyed.

What will happen to the results of the research project?

The findings will be presented nationally and internationally at academic conferences, to NHS organisations and submitted for publication in academic journals. The aim of this will be to inform NHS practice and service developments for people with dementia. Participants in the study will not be identifiable in any of the reported material. A summary of findings will be shared with you if you request this.

A full report will be included in a thesis submitted for examination as part of a PhD. This is due for completion in 2020. This will be available online via http://etheses.whiterose.ac.uk/

Who is organising and funding the research?

This research has partly been funded by the National Institute of Health Research, as this organisation funded another research study called 'Valuing Active Life in Dementia' (VALID), for which I worked as a paid member of research staff. That work led my undertaking this PhD research project, partly while a paid member of research staff.

Who has ethically reviewed the project?

This project has been reviewed and approved by North West Greater Manchester East Research Ethics Committee (Reference Number: 17/NW/0414), the Health Regulation Authority and Rotherham Doncaster and South Humber NHS Foundation Trust , and Sheffield Health and Social Care NHS Foundation Trust.

Please contact me if you have any questions about this research.

Becky Field

<u>Telephone</u>: 0114 222 2985 Email: <u>b.field@sheffield.ac.uk</u>

Address: School of Health & Related Research (ScHARR)
University of Sheffield, Regent Court, 30 Regent Street,
Sheffield S1 4DA

THANK YOU FOR TAKING THE TIME TO CONSIDER THIS RESEARCH

Have you been diagnosed with dementia in the last two years or so?

Would you like to share your experiences and views about support and services offered to people with dementia after diagnosis?

If so….

I would like talk to you (either alone or together with another person of your choosing) about support and services offered to people after a diagnosis of dementia.

If you would like more information, please do get in touch!

You can telephone Becky Field on: 0114 222 2985
Or email: b.field@sheffield.ac.uk
Or tell a member of staff and they can contact me on your behalf

This is part of a PhD research project at the University of Sheffield

Appendix 3.6 Confirmation of appointment   [Appointment letter v1 10.05.2017]

The
University
Of
Sheffield.

<div align="right">

Becky Field
☎ 0114 222 2985
✆ b.field@sheffield.ac.uk [edit as appropriate]
✉ School of Health and Related Research, University of Sheffield
Regent Court, 30 Regent Street,
Sheffield S1 4DA

</div>

NAME XXXXXXX
ADDRESS XXXX
Date

Dear NAME and/or NAME (delete as appropriate); two separate letters if required for person with dementia and carer if living separately)

Research project: A study to explore how people with early stage dementia respond to offers of support and services

Thank you for speaking to me on the telephone on [date] / I spoke with [name of person spoken to] by telephone on [date] [delete as appropriate].

We talked about the research study I am carrying out about support and services offered to people with dementia after diagnosis. You [both delete as appropriate] kindly agreed to participate in a face to face interview.

I am now writing to confirm the appointment for the interview.

When: [insert date and time]   Where: [insert]

This interview may take up to one hour.

Please be assured that taking part is completely voluntary and you are under no obligation to take part if you do not feel that this research study is right for you. You do not have to give a reason.

In the meantime, if you have any questions please do not hesitate to contact me by telephone or email:

☎ 0114 222 2985
✆ b.field@sheffield.ac.uk [edit as appropriate]

Yours sincerely,

Becky Field,   PhD student, University of Sheffield

One page summary

Project title: 'A study to explore how people with early stage dementia respond to offers of support and services'

Aim: This project aims to explore and understand how people with early stage dementia respond to offers of support or services in the two years after they have received a diagnosis of dementia. The focus of this research is support and services other than those to do with medication/s that may be prescribed for dementia.

This is a PhD research project, based at the University of Sheffield

What is involved in taking part?

One face to face interview about:

➢ life after receiving a diagnosis of dementia

➢ any services or support that may have been offered

➢ views about the kind of services that may support people living with dementia after diagnosis.

If a person with dementia has a family carer and prefers to be interviewed with them together, then joint interviews will be held.

Interviews may last up to one hour, but could be shorter. Interviews will be audio-recorded.

Background questionnaire: the researcher will also ask the person with dementia or their family carer, if preferred, to answer some questions before the interview. This is to help make sure the person is suitable for this research and provide some back ground information. This can be done over the telephone by post or in person.

Who can take part in this research?

1. People who have received a diagnosis of a dementia within the last two years, and are living in the community (their own homes or sheltered accommodation).
2. Family carers, if the person with dementia wishes to be interviewed with them.

** Anyone who meets the above criteria can take part. Whether or not you have been offered services after diagnosis, or cannot recall being offered anything, or decided not to take up services offered, I would like to hear from you. **

People need to be able to give their informed consent to participate, and be able and willing to participate in an interview either alone or with their family carer.

People with dementia who live in nursing or residential care, or are living with severe dementia, and their family carers, are not suitable to take part in this research.

NHS staff working with people with dementia and their families will also be interviewed as part of this project.

The University Of Sheffield.

Research project: 'A study to explore how people with early stage dementia respond to offers of support or services'

Background Information Questionnaire

For office use: study ID......

Date of completion:............

Purpose of questionnaire:
This aim of this questionnaire is to help establish that this research project is suitable for you, and to provide some background information about people taking part.

This can be completed by the person living with dementia, or someone else (such as a spouse, family carer, friend or relative) can complete it on their behalf
----

Q1) Have you received a diagnosis of dementia? *(Please circle your answer)*
    YES / NO

Q2) When was this diagnosis of dementia given? (An approximate date or year is fine) *(Please write here)*

....

Q3) What type of dementia was diagnosed? *(Please circle your answer)*

Alzheimer's Disease   /   Vascular Dementia   / Frontal-temporal dementia / Dementia with Lewy bodies / Mixed type dementia -please
describe:................ .... / Other type of dementia - please
describe:.. / Don't know

Q4) How old are you? *(Please write here)* ....

Q5) How would you describe your ethnicity? *(Please write here)*

....

Q6) What was your occupation at retirement? *(Please write here)*

....

Q7) Do you have any other medical conditions, or physical or sensory difficulties (such as being hard of hearing or deaf, visual impairments or mobility difficulties)
(Please circle your answer)
YES / NO
If YES, please describe: *(please write here)*
....
....
....
....

About the family carer, supporter, friend or relative

This part is to be completed if the person with dementia wants to take part in a joint interview together with a person of their choosing

Q1) What is your relationship to the person with dementia? *(Please write here)*

 ....

Q2) How old are you? *(Please write here)*

....

Q3) How would you describe your ethnicity? *(Please write here)*

....

Q4) What is your current occupation or what was your occupation at retirement? *(Please write here)*

....

Q5) Do you have any other medical conditions, physical or sensory difficulties (such as being hard of hearing or deaf, visual impairments or mobility difficulties)?

(*Please circle your answer)*

YES / NO
If YES, Please describe *(please write here)* ....
....
....
....
....
....

If you are completing this to return by post, please return in the stamp addressed envelope provided to: Becky Field, ScHARR, University of Sheffield, Regent Court, 30 Regent Street, Sheffield S1 4DA

_____

For office use only:

PWD M/F FC M/F   Area/Location..............;   Serial number:

The University Of Sheffield.

<div align="right">

Becky Field

☎ 0114 222 2985

b.field@sheffield.ac.uk [edit as appropriate]

School of Health and Related Research, University of Sheffield

Regent Court, 30 Regent Street,

Sheffield S1 4DA

</div>

NAME XXXXXXX
ADDRESS XXXX

Date

Dear NAME and/or NAME (delete as appropriate); two separate letters if required for person with dementia and carer if living separately)

Research project: 'A study to explore how people with early stage dementia respond to offers of support or services'

Thank you for speaking to me on the telephone on [date] / I spoke with [name of person spoken to] by telephone on [date] [delete as appropriate]. We talked about the research study I am carrying out about support and services offered to people with dementia after diagnosis. You [both] [delete as appropriate] said you may be interested in being interviewed for my study.

Therefore, please find enclosed some further information. This explains what is involved in taking part. I will telephone you again [within one week/by agreed date] to discuss whether you may like to take part, or not.

Please be assured that taking part is completely voluntary and that you are under no obligation to take part if you do not feel that this research study is right for you. You do not have to give a reason.

In the meantime, if you have any questions please do not hesitate to contact me:

☎ 0114 222 2985

b.field@sheffield.ac.uk

Yours sincerely,

Becky Field, PhD student, University of Sheffield

Appendix 3.9.1 Covering letter for potential participants from 'Join Dementia Research'

Becky Field
School of Health and Related Research (ScHARR)
The University of Sheffield, Regent Court, 30 Regent Street
Sheffield S1 4DA
Telephone: 0114 222 2985
Email: b.field@sheffield.ac.uk

NAME XXXXXXX
ADDRESS XXXX
Date
Dear NAME and/or NAME (delete as appropriate); two separate letters if required for person

with dementia and carer if living separately)

Research project: A study to explore how people with early stage dementia respond to offers of support or services

I am writing to you after you volunteered to take part in 'Join Dementia Research'.

I am carrying out a study about how people with early stage dementia respond to offers of support or services. I am writing to ask if the person with dementia you support, and yourself, might like to take part.

To participate, the person with dementia needs to be living with early stage dementia, in the community (diagnosed within the last two years, or so) and able to talk to me (participate in an interview), either alone or together with a person of their choosing.

I would be happy to talk to you to see if the study is right for you both. If you would like to call me or email, we could arrange to talk by telephone, if you would like that.

If you do not reply, I may try to telephone you direct as recommended by 'Join Dementia Research'. I do hope that's OK.

I have included the study information with this letter.

I look forward to hearing from you.

With best wishes
Yours sincerely

Becky Field, Researcher, Occupational Therapist and PhD student
School of Health and Related Research (ScHARR), The University of Sheffield

Appendix 3.10 Lay summary for 'Join Dementia Research'

Project title: A study to explore how people with early stage dementia respond to offers of support and services.

What is this research about?
This research is about how people living with early stage dementia, who have received a diagnosis of dementia in the last two years, respond to offers of support from NHS services.

Why do this research?
It is unclear why some people living with early stage dementia take up offers intervention and support and others do not.
Government health policy recommends that the NHS offer support to people after they have received a diagnosis of dementia. There is also evidence that interventions designed for people with early stage dementia, living in the community, can help improve or maintain cognitive skills (such as memory and concentration), people's quality of life and level of independence with daily living skills. Yet, NHS provision of such support services is still developing.

This project aims to explore and understand how people with early stage dementia respond to offers of support or services, after they have received a diagnosis of dementia.

This is a PhD research project, based at the University of Sheffield.

What is involved in taking part?

One face to face interview: people living with early stage dementia will be interviewed about:

> ➢ life after receiving a diagnosis of dementia,
> ➢ any services or support that may have been offered (focusing on support other than those to do with medication/drugs)
> ➢ views about the kind of services that people think may like and could support people with dementia after diagnosis.

- If a person with dementia has a family carer and prefers to be interviewed with them, then joint interviews will be held.

- Interviews may last up to one hour, but can be less.

- Interviews would be audio-recorded.

- Interviews will be carried out in people's own homes or a location of their choice, at a time convenient to them.

Some short background questions: the researcher will ask the person with dementia or their family carer, to answer a few questions when meet or speak by phone. Questions will be about approximate date of diagnosis, type of dementia diagnosed, and some other background information.

NHS staff working with people with dementia and their families will also be interviewed as part of this project.

Who can take part in this research?
People who have received a diagnosis of a dementia within the last two years, or so, and are living in the community.
Family carers, if the person with dementia wishes to be interviewed with them. 'Family carers' can be spouses, relatives, or friends and over 18 years old. They can live with a person with dementia, or not.

*** People do not need to have taken part in any support services after diagnosis to take part in this research ***

People need to be able to give informed consent to participate, and be able and willing to participate in an interview either alone or with their family carer.

People with dementia who live in nursing or residential care, or are living with severe dementia, and their family carers, are not suitable to take part in this research.

What are the benefits of this research project?
Whilst there are no immediate benefits it is hoped this research will contribute to improving understanding of what helps people with dementia take up offers of support.

What happens to the results of this research?
The main findings will be published in academic journals and presented at conferences, to contribute to the evidence about how to support people after a diagnosis of dementia.
A full report will be included in a thesis for examination as part of a PhD. This is due for completion in 2020. This will be available online via http://etheses.whiterose.ac.uk/

Capacity assessment to participate in research

If I am in any doubt as to whether a person has capacity to consent to participate in this research, I will explain that I am unsure this research and taking part in the interview is appropriate and need to discuss it with my supervisors.

Participant ID: _ _ _ _ _ _ _   **Date of assessment:** _ _ / _ _ / _ _

1. Does the participant **understand** the information you have told them that is relevant to their participation in the study?

   Yes ☐ No ☐

   Comments: _____

2. Can the person **retain** the information long enough to make a decision about participation?

   Yes ☐   No ☐

   Comments: _____

3. Can the person **weigh up** the information provided to make a decision about participation?

   Yes ☐   No ☐

   Comments: _____

   _____

4. Can the person **communicate** their decision about participation?

   Yes ☐   No ☐

   Comments: _____

   _____

5. Do I believe the person has the capacity to consent to participate?

   Yes ☐   No ☐

Appendix 3.12 Consent form - people with dementia   [consent form pwd v3 09.08.2017]

Participant Consent Form: for person with dementia

Title of research project: 'A study to explore how people with early stage dementia respond to offers of support or services'

Name of Researcher: Becky Field

Participant Identification number for this project: *Please initial box*

1. I confirm that I have read and understand the information sheet
    dated 01.08.2017 explaining the above research project
    and I have had the opportunity to ask questions about the project.

2. I understand that my participation is voluntary and that I am free to withdraw
    at any time without giving any reason and without there being any negative
    consequences. In addition, should I not wish to answer any particular
    question or questions, I am free to decline.

3. I agree for the face to face interview I participate in to be audio recorded.

4. I understand that the audio recording of the interview will be
    destroyed after completion of the project.

5. I understand that my responses will be kept confidential. I give permission for
    members of the research team to have access to the recording and anoymised
    transcript of the interview. I understand that my name will not be linked with the
    research materials, and I will not be identified or identifiable in reports from the research.

6. I understand that relevant sections of the data collected about me during the study, may be
    looked at by individuals from regulatory authorities or from the   NHS Trust, where it is relevant
    to my taking part in this research. I give permission for these individuals to have access to my
    records.

7. I agree I may be contacted in future, by the researcher. At that time I may be asked
    if I wish to comment on the initial, main findings, either by email or post, or in
    person.

8. I would like to receive a summary of main findings at the end of the project.

9. I agree for the data collected from me to be used in future research.

10. I agree to take part in the above research project.

_____ _____ _____

Name of Participant   Date   Signature

_____ _____ _____

 Lead Researcher   Date   Signature

To be signed and dated in presence of the participant

Participant Consent Form: for family carer/supporter

Title of research project: 'A study to explore how people with early stage dementia respond to offers of support or services'

Name of Researcher: Becky Field

Participant Identification Number for this project: *Please initial box*

1. I confirm that I have read and understand the information sheet dated 01.08.2017 explaining the above research project and I have had the opportunity to ask questions about the project.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline.

3. I agree for the face to face interview I participate in to be audio recorded.

4. I understand that the audio recording of the interview will be destroyed after completing the project.

5. I understand that my responses will be kept confidential. I give permission for members of the research team to have access to the recording and anoymised transcript of the interview. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in reports from the research.

6. I understand that relevant sections of the data collected about me during the study may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my participating in this research. I give permission for these individuals to have access to my records.

7. I agree I may be contacted in future, by the researcher. At that time I may be asked if I wish to comment on the initial, main findings, either by email or post, or in person.

8. I agree for the data collected from me to be used in future research.

9. I would like to receive a summary of main findings at the end of the project.

10. I agree to take part in the above research project.

_____   _____   _____

Name of Participant   Date   Signature

_____   _____   _____

 Lead Researcher   Date   Signature

To be signed and dated in presence of the participant

Appendix 3.14 Indicative Topic guide for interviews (people with dementia or joint interviews) [Topic guide pwd or dyads v1 10.05.2017]

Indicative topic guide for people with dementia (and dyad interview if preferred)

The aim of this topic guide is to indicate the main type of questions and topics to be covered. The researcher will need to adapt the questions as needed to the situation and context of each interview.

INTRO: After consent process, re-orientate to purpose of interview & project

I want to interview you today about any services you may or may not have been offered since you were given a diagnosis of dementia. I am interested to hear about any support or services you may have offered that are NOT to do with your medication / monitoring medication).

If you have difficulty remembering about this, that's OK I am interested in your views about this topic, whether or not you were offered or have taken part in any services offered.

[Keep PIS or summary sheet to hand. Have blank paper and pen to hand, ask if helpful to note key points]

Reassure re: confidentiality & anonymity; no right or wrong answers; we'll take our time; can take a break at any time, if you don't want to answer any questions that's fine. Really want to hear from you about your experiences, after being diagnosed with dementia

If this is a dyad interview: aim the questions at the person with dementia but include and listen to the family carer as well [pre interview contact will have given some information about how the person with dementia expresses themselves and role of family carer in supporting them]

Turn on tape recorder

Warm up: Can you tell me a little about yourself [or yourselves]

E.g. How do you like to spend your time, what you used to do for work ….? Married / children, chat, establish rapport and get to know them a little

Intro question:

> **Open question - if appropriate:**

> Can you tell me a little about how life has been since you were given a diagnosis of dementia?

> Prompts: please tell me more about this; can you give me an example

> **Closed questions - if needed:** Has life changed since diagnosis?

> Prompts: what has changed? E.g. noticed difficulty with memory/ what you can do day to day?

Main question: offer & take up of psychosocial interventions

Open question - if appropriate: Can you tell me about any support or services you have been offered since the diagnosis of dementia was made?

Closed questions - if needed:

Do you attend [name specific local services if known/use photos] e.g. memory services /Alzheimer's Society?

If dyad interview: do you attend together /see the staff together or separately

Prompts:

Can you tell me about that? / What do you go to memory services for (prompt for more info if talk about psychosocial intervention/ support /non pharmacological input]

Prompts if needed:

- Medication review only or other things?
- Who do you see when you? How often?
- Do you go to any groups at memory services? Prompt re: what the group is/does [name specific groups if known]
- Do you see a doctor/ nurse/ occupational therapist/ psychologist [name specific types of staff if known, specific types of 1:1 intervention if known e.g. counselling/ CBT]
- Do any health or social car professionals come and see you at home?

If person and/or dyad DO talk about having been offered or attending support or services:

- Who offered?
- At what point after diagnosis?
- What was offered?
- Did you say yes to taking part straight away?
- If no....explore

Follow up questions

If DO report attending/participating in psychosocial intervention:

What do you think led you to take part in /attending / joining ..... [name specific intervention /service if known]?

Probe: Individual staff approach - was there anything they (service/person) did that was especially helpful to encourage you?

Probe: intervention characteristics: was there anything about [intervention type]... that appealed to you? e.g. Group/individual, location, ease, social contact, information/education, meeting others, help with memory, help with behaviour, help with daily tasks e.g. cleaning, self-care, shopping, travel

Probe: individual or dyad characteristics: do you think there was something about how your life was, at that time, which encouraged you to join/ attend [name intervention/service] E.g.: Wanting support? Wanting info? Feeling isolated? Worried?

If report being offered but DID NOT ATTEND / DECLINED: what do you think led to you deciding against xxx …

Prompts as above

If report were NOT OFFERED anything / can't recall AND ASK ALL PARTICIPANTS:

Open question if appropriate: Since the diagnosis of dementia, what would you have liked to been offered? If anything?

Closed questions if needed: would you have liked someone to offer you support with

- Keep doing your personal interests / hobbies [name specific activities / roles if known]
- Getting out in your local area
- Meeting people – in general / people in similar situations
- Physical exercise / help to keep active physically or with balance
- Mental stimulation – using memory and thinking skills to do things like crosswords, quizzes, games/cards
- Personal care
- Looking after the house / garden
- Support to manage health generally / other health issues
- Anything else

Probe:

- What type of service do you think should offer such support [name specific support talked about if possible]?
- Any particular professional?
- At what point after diagnosis would it be helpful to you / others?
- Location?

Would anything else help you say yes to attending/ joining/ take up offers of support like we've talked about? / Would anything in particular encourage you to give such support or services a go?

Prompts: being offered at particular location/ service; a certain time points in their lives / by phone /letter/ face to face; being offered more than once; service keeping in touch even if say no at first?

Possible probe throughout: if people talk about non NHS services or support explore what these are and what is helpful about them

<u>Final question</u>

If you had to advise other people recently diagnosed with dementia, about how to live well as possible, what would you say to them?

- **Would you say anything about how they should respond if offered support or services by staff in NHS/voluntary sector?**

Anything else?

Closing:

If you think of anything else afterwards that you want to tell me about – you can email or write it down. Would you like a SAE and piece of paper?

- **Remind re: confidentiality & anonymity.**
- **Remind this is part of a PhD research project aiming to inform understanding about the perspective of people with dementia (and family carers if dyad interview) about what helps people with dementia take up offers of support and kinds of services they may want.**
- **If want copy of main findings – will send. If consented to be contacted again – may do that to ask for feedback on main findings.**
- **Thank you for time**

Becky Field (PhD student researcher) visited you

on: …………………………...........................

We talked about

....

……………………………………………………………………………………

……………………………………………………………

We agreed it was best if I visited again.

You do not have to take part if you feel the study is not right for you. **I will visit / telephone you**

on: ....…………………………………………................

....

You can contact me, Becky Field on:

✆Tel: 0114 222 2985

✆ Email: b.field@sheffield.ac.uk[edit as appropriate]

Thank you very much.

<div align="right">
Becky Field

☎ 0114 222 2985

🖰   b.field@sheffield.ac.uk [edit as appropriate]

✉ School of Health and Related Research, University of Sheffield

Regent Court, 30 Regent Street,

Sheffield S1 4DA
</div>

NAME XXXXXXX
ADDRESS XXXX

Date

Dear NAME and/or NAME (delete as appropriate); two separate letters if required for person with dementia and carer if living separately)

Research project: A study to explore how people with early stage dementia respond to offers of support and services

I am writing to say thank you very much indeed for participating in the interview you gave on [insert date] as part of the above research project. Your contribution to this study is greatly appreciated.

If you have any questions about this research, please do not hesitate to contact me

☎ 0114 222 2985
🖰   b.field@sheffield.ac.uk [edit as appropriate]

With very best wishes,

Yours sincerely,

Becky Field, PhD student, University of Sheffield

Appendix 3.17 Consent form for managers

Title of research project: 'A study to explore how people with early stage dementia respond to offers of support or services'
Verbal Consent Form – for managers /gatekeepers

Name of Researcher: Becky Field

Identification Number: **[Researcher to initial boxes]**

1. Participant confirms that the above research project has been explained and they have had the opportunity to ask questions about the project.

2. Participant understands that participation is voluntary and they are free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, if wish they do not have to answer any particular question or questions, and are free to decline.

3. Participant understands that the researcher will make notes about what they say and these notes will be anoymised and destroyed once the project is complete.

4. Participant understands that their name will not be linked with the research materials, and they will not be identifiable in any report/s that result from research.

5. Participant agrees to be contacted in future, by the researcher. At that time they may be asked if they wish to comment on initial findings. If they do not wish so, they are free to decline at that time.

6. Participant would like to receive a summary of main findings at the end of project.

7. Participant agrees for data collected from them to be used in future research.

8. Participant agrees to take part in the above research project.

_____   _____

Name of Participant   Date

Verbal consent taken over telephone by researcher: I confirm I have explained the above points to the participant and gained verbal consent

_____   _____   _____

 Lead Researcher   Date   Signature

To be signed and dated by researcher whilst talking to the gatekeeper / manager on the telephone

Appendix 3.18 Indicative brief topic guide for managers interviews

Indicative brief topic guide for short interviews with mangers or gatekeepers of services for people with early stage dementia

The aim of this topic guide is to indicate the main type of questions and topics to be covered. The researcher will need to adapt the questions as needed to the situation and context of each interview

Aims of interview:

1) gain overview of psychosocial interventions and services offered to people with early stage dementia in their service

2) whether I can have their agreement to approach NHS to be interviewed, and if so, how best to approach them

   Introduction and telephone consent process – introduce self and project; make clear have their NHS trust R&D support and NHS ethics; seek telephone consent as per consent form and tell them will send copy of consent form by post or email

Q1) Please can you tell me about the kinds of psychosocial interventions / support or services that are offered by your service for people after diagnosis, with early stage dementia

- are there any other key services in the area that you are aware of / that your service works with / signposts people to e.g. voluntary sector)

Q2) What kinds of staff provide these interventions (how many, type of profession, locations)

Q3) I would like to interview NHS staff about their experiences of either offering, referring to or providing psychosocial interventions to people with early stage dementia – can I approach some of your staff to invite them to participate in an interview

[Suggest likely to be half hour telephone interview, but can do face to face group interviews if staff or manager prefer – will come or do at time that suits them,

What is best method of reaching them / what are their contact details?

Thank for time and assistance

Invitation for staff to participate in interview [email or letter]

[insert researcher name, address, tel number and email if letter]

[insert date if letter]

Dear [staff name if known]

[email subject /header for letter]

Please share your expertise! I want to hear about your work with people with early stage dementia.

Would you be willing to be interviewed by telephone, face to face or as part of a group [delete as appropriate] about offering or signposting to psychosocial interventions for people with dementia?

[If face to face or group interview **lunch or refreshments provided!**]
If group interview: A time and date suitable for most people will be arranged.
[Delete as appropriate]

I want to interview staff working with people with dementia. Health policy now recommends post diagnostic support and psychosocial interventions for people with early stage dementia, so this project aims to contribute to the growing evidence base for interventions for this client group and increase understanding about what may support them.

This is part of a PhD research study exploring influences on take up of psychosocial interventions, by people with early stage dementia.

If you are interested in taking part, please read the attached information sheet and contact me...

Becky Field b.field@sheffield.ac.uk Telephone: 0114 222 2985
[edit as appropriate]
Thank you for reading (delete if letter)
Best wishes
Becky Field
PhD student, School of Health and Related Research (ScHARR)
The University of Sheffield 0114 222 2985 b.field@sheffield.ac.uk [edit as appropriate]

The
University
Of
Sheffield.

Participant Information for staff

Research project title: A study to explore how people with early stage dementia respond to offers of support and services.

Invitation

You have been invited to take part in an interview as part of this research project. 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. Please ask me if there is anything that is unclear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the research?

This research is exploring how people with dementia respond to offers of support or services provided by the NHS.

I want to understand more about how people with dementia respond to offers of support or services after diagnosis. This is because health policy promotes support for people after diagnosis. Also, research evidence suggests that people with dementia and their carers can benefit from services aimed to support them, for example when interventions are aimed at improving thinking skills such as memory, daily living skills or quality of life. However, such NHS services for people with dementia are still developing.

I will be writing up the project as part of a PhD at the University of Sheffield.

Why have I been chosen?

You were suggested for this for this research because you are a member of staff who works with people with early stage dementia.

Staff from different professional backgrounds and/or settings are being invited to take part. The plan is to interview up to 10 staff participants over the telephone, or in face to face individual or group interviews. People with dementia, and their family carers, if they wish, are also being asked to take part.

Do I have to take part?

It is up to you to decide whether or not to take part in this research. You can withdraw at any time without giving a reason.

What will happen to me if I take part?

If you take part in a telephone interview or a face to face individual or group interview, you will be asked about your role, and to talk about your views and experiences of psychosocial interventions. The focus of this study is on services offered to people after a diagnosis of dementia. There are no right or wrong answers.

A telephone interview should take 30-45 minutes and face to face individual or group interviews about one hour. Time, dates and location will be arranged to be convenient as possible and to minimise any impact on service provision. Lunch and/or light refreshments (depending on the time of day) will be provided if a face to face or group interview takes place.

Becky Field (PhD student) will carry out the interviews. If a group interview takes place another member of University of Sheffield staff or student may also attend as a co-facilitator.

You will be given a copy of this information sheet to keep and if you decide to take part, a copy of your consent form (telephone consent given for telephone interviews or signed consent for face to face or group interviews).

Will I be recorded, and how will the recordings be used?

The interviews will be audio recorded. These will then be transcribed, and anonymised so that any personal details which could identify you are removed. Transcripts will be analysed to identify key issues affecting people's readiness to engage in psychosocial interventions, after diagnosis. The audio recordings will be used only for analysis. No one outside the project will be allowed access to the recordings.

What are the possible disadvantages and risks of taking part?

There are no foreseen disadvantages or risks in taking part.

What are the possible benefits of taking part?

Whilst there are no immediate benefits for people participating in this project, it is hoped this work will contribute to enhanced understanding of the perspectives of people with early stage dementia and the evidence base for psychosocial interventions for people living with early stage dementia and their family carers.

What if something goes wrong?

If you wish to make a complaint about this research please contact the project supervisors: Professor Gail Mountain g.a.mountain@sheffield.ac.uk or Dr Elizabeth

Coates e.coates@sheffield.ac.uk University of Sheffield, School of Health and Related Research (ScHARR) Telephone 0114 222 0886 or Dean of ScHARR, Professor John Brazier, University of Sheffield Regent Court, 30 Regent Street, Sheffield, S1 4DA telephone (0114 222 5446 - Dean's Office)

Will my taking part in this project be kept confidential?

Any information that I collect from you during the course of the research will be treated in confidence. It will not be possible to identify individual participants in any reports or publications.

Who will have access to the data and where will it be held?

All data, including audio recordings and transcripts of interviews will be treated confidentially, and held on secure computer drives and password protected computers at the University of Sheffield. Transcripts of the interview will be anonymised, so that your name or any other identifying details will be removed from the interview transcript. Audio recordings of interviews will be stored securely on a password protected computer s at the University of Sheffield until the project is completed and then they will be destroyed. Only the project team and a professional transcriber will have access to the data. Any professional transcriber employed will have completed information governance and data protection training required by the University of Sheffield. Paper copies of transcripts will be kept in a locked filing cabinet. Also, your contact details will be stored securely on a password protected computer at the University of Sheffield until the project is complete and then destroyed. Consent forms and anonymised interview transcripts will be kept for five years after completion of the project, and then destroyed.

What will happen to the results of the research project?

The findings will be presented nationally and internationally at academic conferences, to NHS organisations and submitted for publication in academic journals. The aim of this will be to inform NHS practice and service developments for people with dementia. Participants in the study will not be identifiable in any of the reported material. The researcher will send participants and participating services a summary of main findings if requested.

A full report will be included in a thesis submitted for examination as part of a PhD. This is due for completion in 2020. This will be available online via http://etheses.whiterose.ac.uk/

Who is organising and funding the research?

This research has partly been funded by the National Institute of Health Research (NIHR), as this organisation funded another research study called 'Valuing Active Life in Dementia' (VALID) (NIHR Grant number RP-PG-061010108), for which I worked as a paid member of research staff. That work led my undertaking this PhD research project part time whilst a paid member of research staff.

Who has ethically reviewed the project?

This project has been approved by North West Greater Manchester East Research Ethics Committee (Reference Number: 17/NW/0414), the Health Regulation Authority, Rotherham Doncaster and South Humber NHS Foundation Trust and Sheffield Health and Social Care Foundation NHS Trust.

Contact for further information

Supervisors for Becky Field, PhD student:
Dr Elizabeth Coates 0114 222 0886 e.coates@sheffield.ac.uk / Professor Gail
Mountain: g.a.mountain@sheffield.ac.uk
School of Health and Related Research (ScHARR)
University of Sheffield
Regent Court, Regent St
Sheffield S1 4DA

THANK YOU FOR TAKING THE TIME TO CONSIDER THIS RESEARCH
Thank you for reading this.

Becky Field

PhD student, University of Sheffield b.field@heffield.ac.uk / 0114 222 2985
Address: School of Health & Related Research (ScHARR)
University of Sheffield, Regent Court, 30 Regent Street, Sheffield S1 4DA

Appendix 3.21 Consent form for staff [Consent form staff v3 09.08.2017]

The University Of Sheffield.

Participant Consent Form – Staff interviews

Title of Research Project: 'A study to explore how people with early stage dementia respond to offers of support or services'

Name of Researcher: Becky Field

Participant Identification Number for this project: *Please initial each box*

Consent by telephone taken?   Yes ☐ *No* ☐
[NB: If telephone interview: researcher to take verbal consent by telephone and initial box]

1. I confirm that I have read and understand the information sheet [v3 09.08.2017] explaining the above research project and have had the opportunity to ask questions about the project. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. ☐

3. I agree for the telephone interview, group or face to face interview I participate in to be audio recorded. ☐

4. I understand that my responses will be kept strictly confidential.
   I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. ☐

5. I understand that relevant data collected from me may be accessed by regulatory authorities and the NHS trust. I give my permission for this. ☐

6. I agree that I may be contacted in future to seek my feedback on main findings. I understand that I can decline if I do not wish to contribute at that time. ☐

7. I agree for the data collected from me to be used in future research. ☐

8. I would like to receive a summary of main findings when the project is complete ☐

9. I agree to take part in the above research project. ☐

Name of Participant   Date   Signature *(if face to face interview)*

_____   _____   _____

Name of person taking consent   Date   Signature

_____   _____   _____

(if different from lead researcher) *To be signed & dated in presence of participant if face to face interview, if telephone interview, person taking consent to date & sign.*

_____ _____ _____

 Lead Researcher   Date   Signature

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Appendix 3.22 Indicative topic guide for staff interviews and focus group
[Indicative topic guide staff v1 10.05.2017]

Indicative topic guide - for interviews with NHS or other staff

(Likely telephone interviews but could be face to face or group interviews if preferred by participants or NHS service)

The aim of this topic guide is to indicate the main type of questions and topics to be covered. The researcher will need to adapt the questions as needed to the situation and context of each interview.

Introduction: Introduce self and aim of project. Reiterate confidentiality and anonymity.

Aim of interview: to seek their views and experiences of offering, referring or providing psychosocial interventions (not pharmacological intervention).

My PhD research is about what helps people with early stage dementia take up psychosocial intervention so it is really helpful to get your views. Hope that findings from this research will contribute to the evidence base around support and interventions for people with early stage dementia - by trying to understand what helps people feel ready to accept offers of psychosocial intervention.

Remind that there are no right or wrong answers and agreed duration of interview. Anything said be treated confidentially. The transcript will be anonymised, any personal details which could identify removed.

Turn on recorder

Warm up: tell me a little about yourself, in terms of your work role with people with dementia e.g. the type of work you do, how long you have been in post

Prompt for profession, grade, time worked in current post,

Intro question: Do you offer, refer to or provide any psychosocial interventions

Prompt re: what are the interventions offered, by who to who, when (time points post diagnosis) where and how (the process e.g. formal referral process/informal), who provides e.g. NHS or third sector? What disciplines involved in what setting?

If not able to give any examples prompt: support or education groups, Alzheimer's society cafes,   and Occupational therapy intervention? Psychology intervention? CST group? Packs/leaflets given?

Main question 1:

In your experience or role [referring/offering/providing/other] ....

What do you think influences people with early stage dementia (I mean people who are roughly 2 years post diagnosis, living at home take up or reject offers to [name specific intervention/s talked about, if there are several offered, go through them one by one asking same question] ?

Prompts: role/influence of carer; role/influence of what is offered (type of intervention); influence of who offers it (e.g. doctor/nurse/ OT/psychologist ; when after diagnosis; setting

in which it is offered; influences of consequences of dementia [e.g. memory loss, impaired organizational skills, low mood, ? self-awareness or acceptance of diagnosis

Main question 2: What do you think are the main things that influence you in referring /offering / signposting / providing psychosocial interventions?

Prompts: are there times when you might NOT offer /refer to/ signpost to / provide psychosocial intervention - what influences that decision?

Closing question:

If you had to say what you thought was the main influence on you referring or signposting to psychosocial interventions, what would it be?

Sum up main reasons and influences – share summary back for comment

Remind re: anonymity and confidentiality. When research is written up you won't be able to tell who participated. Where research will be published and can send summary of findings if requested or come to meeting to feedback if wish for that.

THANK YOU

Appendix 3.23 Details of thematic analysis: coding and theme identification

Appendix 3.32.1 Sample of four pages anonymised transcript from a joint interview (handwritten notes and ideas for initial codes)

P = person with dementia FC1 = family member BF =Becky Field (researcher)

I'll ring you and blah de blah de blah. No she treats me like a grown up person and she always says if there's anything you want tell me because I'm not a mind reader. And we've got a good rapport going on yeah she's brilliant. I mean if they were all like her, people would be a lot better I think.

41.07	BF	So you're daughter is, like you said your rock and you read each other well, you know, so she sort of knows how to talk to you and stuff, but it sounds like from (daughter name) is saying, shall I call you (name?), sounds like from what (name) is saying when they offered you the groups at memory services it sounds like maybe you weren't so keen because of how you felt at the Blind Society?
40.45	P	If they were all like (name) at the Dementia Societies, tret you like grown-ups but it was very
40.40	FC1	You don't know what they are like because you've not been
40.37	P	No but they're patronising (name)
40.35	FC1	That one is, but I mean for me, from my perspective I would love it, if mum got some different input from outside.
40.28	P	I will try it I promise you
40.26	FC1	Because she gets really easily in the house
40.23	BF	Yeah you seem quite a lively person to me, you know, a person who likes to chat and be social, but it's hard, I get it with the sight you know it's a double, it's a bit of a bind isn't it, to find
40.12	FC1	It's just frustrating, I mean really, like mum says, it's like sitting here waiting for godo isn't it, you know, the day will come when me mum's memory might go completely and she'll not really be able to do anything that she can benefit from now, like that's a shame, because I think you know while she can, go out and enjoy things and get to know new people, so I would love to do that and we've got plans of doing that. We went to the memory clinic about 3 weeks ago, 2/3 weeks ago, and they've signed her off now because apparently they've changed the funding haven't they. So it's no longer every six months you go, they are just there on the end of a phone line if you need anything, so it's more like you're in charge of, of being in contact.
39.28	BF	You can call them but they are not going to bring you in as a matter of course
39.25	FC1	And I think that's down to (talking over). So I've got the lunch clubs telephone number but mums going, my sister lives in ~~xxxx~~
39.14 ic	BF	You were just saying weren't you, I was like wow this sound pretty good.
39.11	FC1	Yeah so mums going to ~~xxxx~~ for three weeks. So what's happening I get wheelchair assistance at the airport and go on the plane, because she's absolutely fine at the moment to, so long as they tell you what's on your food tray you'll be alright mum won't you.
38.58	P	Might extend it when I get there stay a bit longer I think.
38.55	BF	And you've been before so this is sort of, you know where you are going to and stuff
38.49		(speaking over each other)
38.47	FC1	My sister will wait for her at the other end, and then my sister was a carer anyway, she kind of, if anybody out the two of us, you know, she's got more patience and yeah she's in good hands with my sister so I don't mind. And you know it's nice to have her independence.
38.22	P	(name) treats me like a grown up, just do that mum don't mess about, do the dishwasher if you want please yourself. But our (name) will say you sit there mum.

change of system / monitoring at m.s.

holiday for P.

holiday plans.

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8.12	BF	And how do you feel about that?
8.11	P	I don't
8.10	BF	Do you like that?
8.09	P	No I don't.
8.07	BF	You want to be as busy as you can be?
8.06	P	You see she looks after her husband and he likes that, he likes babying, and sit in the chair, because he's my age and oh god, she treats him like one of her clients when she were in nursing home and. But i'll just have to put up with that.
.49	BF	Yeah I think that's it isn't it, sometimes with family you have to kind of
.46	P	You can't choose your family can you
.44	BF	You kind of have to accept some things don't you, you know when people have chosen their partners and that sort of thing, it's not always easy I'm sure.
.38	P	It isn't
.37	BF	So I'm interested to, try and get you to think a little bit (name), about your experiences at memory services then? So perhaps when you first went they said you know, we run these groups or? *topic guide* *when I'm allowed*
.23	FC1	Not bothered, not bothered.
.22	P	I weren't at time. I'd go now but I weren't at time because I think you want to dismiss it really and think I'll get better. You know, and you can't talk to anybody about it because they've not been there, so you're thinking well if I go I'm going to be sat amongst these people, it might be worse than (me and I might... . So I just dismissed it. I'm very quick at dismissing things. I'm sorry about that.
.7	BF	That's alright. I think that's everybody's, what's the word?
.3	P	Prerogative
.2	BF	Prerogative. You're allowed to do that aren't. You're also quite reflective on noticing. So you might have dismissed it but you are, yeah, talking to me anyway you're taking a step back aren't you, and thinking hmmm you know.
.1	P	I think if somebody's not patronising you it's brilliant. I mean (name) never patronises me, never ever, because she lets me have my say and then she has her say and then we meet in middle. But when people say
	FC1	No we don't I win
	P	Eh?
	All	(laughter)
	P	You what?
	FC1	I win (laughs)
	P	I know but, I'm still not at, thing where I want to just be seen and just be dominated to because I don't want it. And you don't do it.

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14	BF	And so your expectation is, you know nobody should be patronised. Which is fair enough.
5.06	P	And if you don't agree then fair enough you don't care but
16.02	BF	Can you, I mean I know I know obviously memory might be a little bit difficult for you, but so if you can't remember, you just tell me it's fine, (name) was saying she thinks you know, that maybe your experience of the groups at the blind society perhaps wasn't that positive and that had maybe put you off a bit because you thought they were patronising. Can you remember what it was that happened there that made you think eurgh don't fancy that anymore?
15.39	P	I don't like. It's all sitting round, all having to talk about what they feel because I think it's personal to yourself and I don't think it should voiced on the stage. That might sound awful but
15.23	BF	No I think you're totally entitled to your opinion you know. For you it's sounds, you don't necessarily want to talk about it. Is that what you're saying?
15.12	P	It's as if you've got a bad marriage, you wouldn't like to sit in a group talking about what your husband does and what. I just think it's personal.
15.05	BF	Yeah. Yeah.
15.03	P	Everybody don't feel the same if they're losing their sight or losing their memory. I don't know.
14.58	BF	Yeah yeah that's a really, really fair point.
14.56	P	If there were suddenly a couple in here, going through same thing, I would be willing to sit and discuss it. But I don't want a wider audience.
14.48	BF	So that kind of group thing maybe, isn't always what you are after.
14.44	P	No I'm not
14.44	BF	Not everybody is a group person are they, you know, whereas maybe one on one it seems is more
14.38	P	Or one or two people
14.37	BF	Somebody who
14.34	P	Two or three there I wouldn't mind
14.34inc	BF	But that's enough for you?
14.33	P	Yeah
14.33	FC1	I think what, I think what what mum wants from support is somewhere where she can go and be who she was and who she wants to be rather than being forced into a mould of you know the illness.
14.18	P	Correct (daughters name). Our (Name) knows me more than anybody
14.16	FC1	She doesn't want to be a blind person, she doesn't want to be someone suffering with dementia, she's mum and she wants just to be herself.
14.05	P	And even coming up to 80
14.05	FC1	And sit and do normal things like chat and have lunch or sit and have coffee and just talk about the weather and talk about things that normally people would do when they meet up. Rather than oh here's an activity that we've got you to do to try and help your memory. That's not really what you're after is it?

Handwritten margin notes:
- doesn't like group talking
- re experience in groups
- its private/personal
- doesn't want to share really
- not liking groups
- dementia not being defining thing
- type of activity would like

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Appendix 3.23.2 Sample of four pages anonymised transcript from a joint interview (as coded within NVIVO after codes had been developed iteratively)

43.00   P   I've had nothing. They've never even been to discuss it with (name).

42.56   FC1   Yes they have mum, we've been, we were referred to the memory clinic. So we went to see

42.48   P   That's only now, recent.

42.46   FC1   No that was just after the diagnosis last January, we went, we were referred to the memory clinic we went there, they told us about the different dementia cafes that mum could go to and told her that there were some groups as well that she could get involved with. But at that point you weren't interested in getting involved in any.

42.30   P   No I weren't

42.29   FC1   And I think it was just because of her experience of, she's been to a couple of groups through the Blind Society, and felt like she was being a little bit patronised and been treated, you know, treated a bit like a baby, you know, 'come here (name) and sit down there and I'll get you a cup of tea' and mum, I guess you're used to just being treated normally aren't you, so

42.05   BF   Just wanted to chat and

42.05   FC1   That's it

42.05   P   Well years ago, in my working life I've worked

42.01   BF   What did you used to do for work?

42.00   P   [names previous occupation], working on mental health units. And I used....

            Yeah [hospital name]

41.55   BF   Good for you

41.54   P   I understand all this. But I think, I think, when they think people's, what I've got, they think we are daft an all. You know, 'awww you alright love, what happened'. I can't stand it, you know, (name of daughter) doesn't treat me like that she treats me like, she'll say 'here mother, just get on with it'. And she treats me like I want to be tret, not like a baby and sit there and don't move while I'm at work and I'll ring you and blah de blah de blah. No she treats me like a grown up person and she always says if there's anything you want tell me because I'm not a mind reader. And we've got a good rapport going on yeah she's brilliant. I mean if they were all like her, people would be a lot better I think.

41.07   BF   So you're daughter is, like you said your rock and you read each other well, you know, so she sort of knows how to talk to you and stuff, but it sounds like from (daughter name) is saying, shall I call you (name?), sounds like from what (name) is saying when they offered you the groups at memory services it sounds like maybe you weren't so keen because of how you felt at the Blind Society?

40.45   P   If they were all like (daughters's name) at the Dementia Societies, tret you like grown-ups but it was very

40.40   FC1   You don't know what they are like because you've not been

40.37   P   No but they're patronising (daughter's name)

40.35   FC1   That one is, but I mean for me, from my perspective I would love it, if mum got some different input from outside.

40.28   P   I will try it I promise you

40.26   FC1   Because she gets really [unclear audio BF 12/9/18] easily in the house

40.23   BF   Yeah you seem quite a lively person to me, you know, a person who likes to chat and be social, but it's hard, I get it with the sight you know it's a double, it's a bit of a bind isn't it, to find

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40.12 FC1 It's just frustrating, I mean really, like mum says, it's like sitting here waiting for godo isn't it, you know, the day will come when me mum's memory might go completely and she'll not really be able to do anything that she can benefit from now, like that's a shame, because I think you know while she can, go out and enjoy things and get to know new people, so I would love to do that and we've got plans of doing that. We went to the memory clinic about 3 weeks ago, 2/3 weeks ago, and they've signed her off now because apparently they've changed the funding haven't they. So it's no longer every six months you go, they are just there on the end of a phone line if you need anything, so it's more like you're in charge of, of being in contact.

39.28 BF You can call them but they are not going to bring you in as a matter of course

39.25 FC1 And I think that's down to (talking over). So I've got the lunch clubs telephone number but mums going, my sister lives in [another country] .

39.14 BF You were just saying weren't you, I was like wow this sound pretty good.

39.11 FC1 Yeah so mums going to [country] for three weeks. So what's happening I get wheelchair assistance at the airport and go on the plane, because she's absolutely fine at the moment to, so long as they tell you what's on your food tray you'll be alright mum won't you.

38.58 P Might extend it when I get there stay a bit longer I think.

38.55 BF And you've been before so this is sort of, you know where you are going to and stuff

38.49 (speaking over each other)

38.47 FC1 My sister will wait for her at the other end, and then my sister was a carer anyway, she kind of, if anybody out the two of us, you know, she's got more patience and yeah she's in good hands with my sister so I don't mind. And you know it's nice to have her independence.

38.22 P (FC name) treats me like a grown up, just do that mum don't mess about, do the dishwasher if you want please yourself. But our (name) will say you sit there mum.

38.12 BF And how do you feel about that?

38.11 P I don't

38.10 BF Do you like that?

38.09 P No I don't.

38.07 BF You want to be as busy as you can be?

38.06 P You see she looks after her husband and he likes that, he likes babying, and sit in the chair, because he's my age and oh god, she treats him like one of her clients when she were in nursing home and. But i'll just have to put up with that.

37.49 BF Yeah I think that's it isn't it, sometimes with family you have to kind of

37.46 P You can't choose your family can you

37.44 BF You kind of have to accept some things don't you, you know when people have chosen their partners and that sort of thing, it's not always easy I'm sure.

37.38 P It isn't

37.37 BF So I'm interested to, try and get you to think a little bit (name), about your experiences at memory services then? So perhaps when you first went they said you know, we run these groups or?

37.23 FC1 Not bothered, not bothered.

37.22 P I weren't at time. I'd go now but I weren't at time because I think you want to dismiss it really and think I'll get better. You know, and you can't talk to anybody about it because they've not been there, so

you're thinking well if I go I'm going to be sat amongst these people, it might be worse than (me and I might….
So I just dismissed it. I'm very quick at dismissing things. I'm sorry about that.

36.57   BF That's alright. I think that's everybody's, what's the word?

36.53   P   Prerogative

36.52   BF Prerogative. You're allowed to do that aren't. You're also quite reflective on noticing. So you
might have dismissed it but you are, yeah, talking to me anyway you're taking a step back aren't you, and
thinking hmmm you know.

36.41   P   I think if somebody's not patronising you it's brilliant. I mean (daughetr's name) never
patronises me, never ever, because she lets me have my say and then she has her say and then we meet in
middle. But when people say

36.30   FC1   No we don't I win

36.29   P   Eh?

36.27   All (laughter)

36.27   P   You what?

36.26   FC1   I win (laughs)

36.25   P   I know but, I'm still not at, thing where I want to just be seen and just be dominated to because I
don't want it. And you don't do it.

36.14   BF And so your expectation is, you know nobody should be patronised. Which is fair enough.

36.06   P   And if you don't agree then fair enough you don't care but

36.02   BF Can you, I mean I know I know obviously memory might be a little bit difficult for you, but so if
you can't remember, you just tell me it's fine, (name) was saying she thinks you know, that maybe your
experience of the groups at the blind society perhaps wasn't that positive and that had maybe put you off a bit
because you thought they were patronising. Can you remember what it was that happened there that made you
think eurgh don't fancy that anymore?

35.39   P   I don't like. It's all sitting round, all having to talk about what they feel because I think it's
personal to yourself and I don't think it should voiced on the stage. That might sound awful but

35.23   BF No I think you're totally entitled to your opinion you know. For you it's sounds, you don't
necessarily want to talk about it. Is that what you're saying?

35.12   P   It's as if you've got a bad marriage, you wouldn't like to sit in a group talking about what your
husband does and what. I just think it's personal.

35.05   BF Yeah. Yeah.

35.03   P   Everybody don't feel the same if they're losing their sight or losing their memory. I don't know.

34.58   BF Yeah yeah that's a really, really fair point.

34.56   P   If there were suddenly a couple in here, going through same thing, I would be willing to sit and
discuss it. But I don't want a wider audience.

34.48   BF So that kind of group thing maybe, isn't always what you are after.

34.44   P   No I'm not

34.44   BF Not everybody is a group person are they, you know, whereas maybe one on one it seems is
more

34.38   P   Or one or two people

34.37   BF Somebody who

34.34   P Two or three there I wouldn't mind

34.34   BF But that's enough for you?

34.33   P Yeah

34.33   FC1   I think what, I think what what mum wants from support is somewhere where she can go and be who she was and who she wants to be rather than being forced into a mould of you know the illness.

34.18   P Correct (daughters name). Our (Name) knows me more than anybody

34.16   FC1   She doesn't want to be a blind person, she doesn't want to be someone suffering with dementia, she's mum and she wants just to be herself.

34.05   P And even coming up to 80

34.05   FC1   And sit and do normal things like chat and have lunch or sit and have coffee and just talk about the weather and talk about things that normally people would do when they meet up. Rather than oh here's an activity that we've got you to do to try and help your memory. That's not really what you're after is it?

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Appendix 3.23.3 Photographs of example of mindmaps used to summarise initial thoughts for themes (solo and joint interviews with people with dementia)
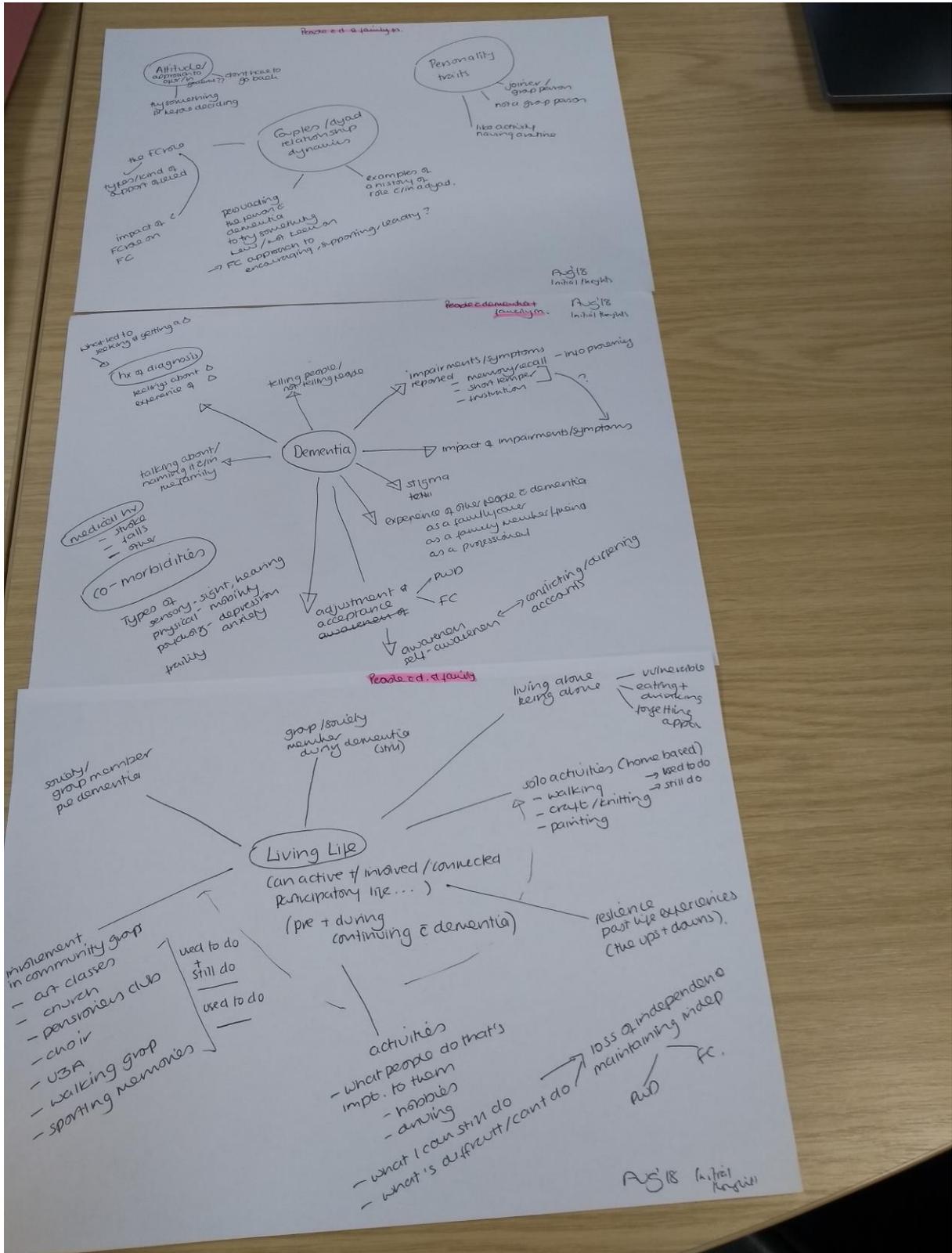
Appendix 3.23.4 Photograph of an example of notes about initial themes (solo and joint interviews with people with dementia)
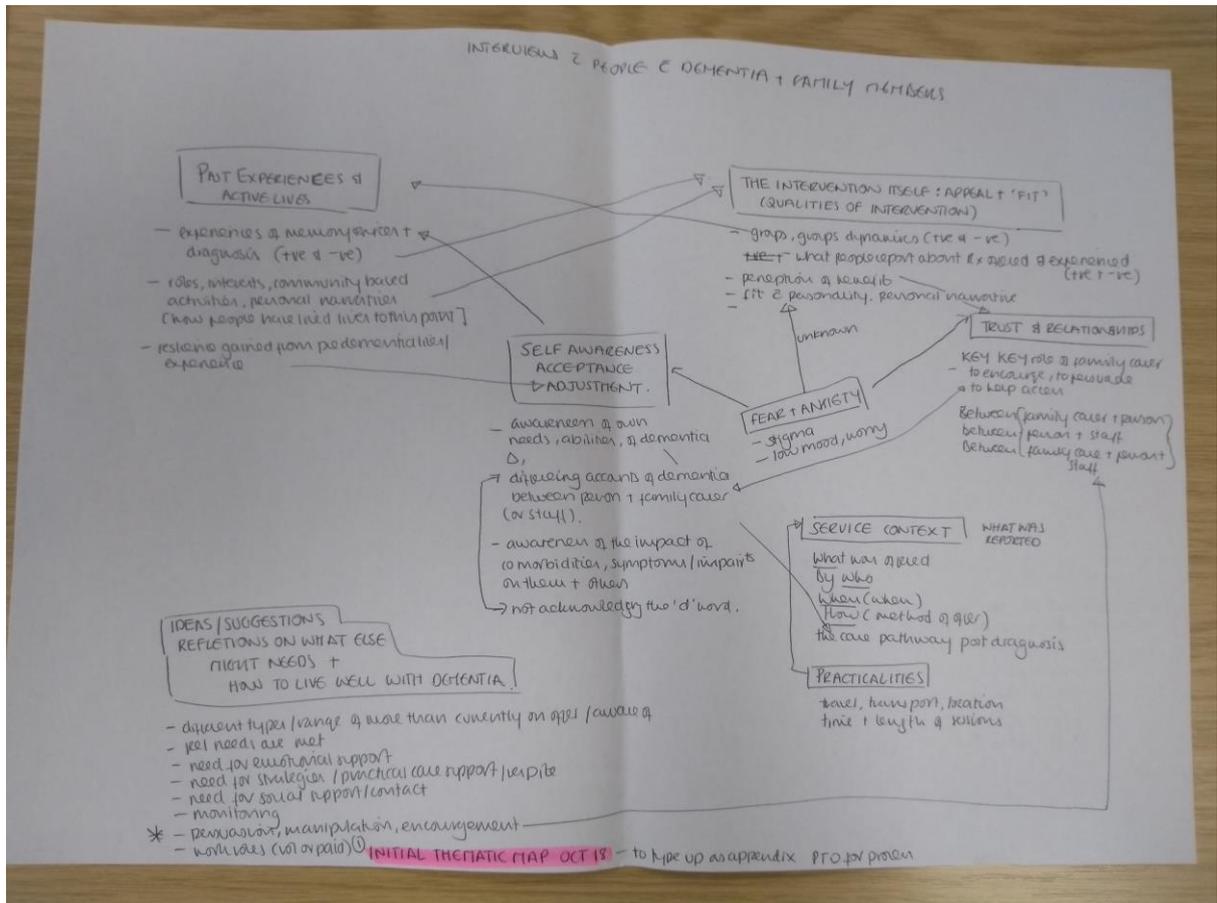
Appendix 3.23.5 Codes used on transcripts from solo and joint interviews with people with dementia and family members

NB: *Solo interview transcripts were coded first. Highlighted words indicate additional initial codes generated from joint interview transcripts*

Community activities	Comorbidities	Dementia experience	Family background and family stories
Church, Home based Community groups, non-dementia, Difficulty accessing, Driving, Other social leisure, Personal interests (creative, IT, mechanics, music dancing song, sport, theatre, travel/trips. Women's guild/institute)	Asthma, breathing Arthritis, Rheumatism, Continence, Diabetes, Epilepsy, Falls, mobility, Heart disease, Vision Medical history	Causes of dementia, Dementia, Medication issues, Diagnosis journey, Diagnosis to tell or not, Impairments, Symptoms and impact, Stigma examples, Naming it	Bereavement and loss, Moving house

Intervention Group dynamics	Independence	Knowing others with dementia	Memory services general
	Isolation, Being alone, Vulnerability, risk, Personal Activities of Daily Living (PADL), Domestic Activities of Daily Living (DADL)		

Methods	Mood issues	No offer due to type of dementia	
Comments on process, Dementia in interview, Adjusting verbally, Set up, Showing pictures, Using written prompts	Anger, Anxiety, worry, Depression, Motivation, Suicidal thoughts		

Reports of NHS offers, NOT engaged	Reports of NHS-offers & engagement	Reports of non NHS	Reports of non-NHS offer & engagement

with		NOT engaged with	
Reasons for not going (travel, enough on, forgot, recall of offers, weather)	Method of offer. Types of NHS intervention: CST, ==Exercise group,== Information sessions, service development/PPI, ==Social support / social events== Views about offers, Views re: hypothetical offers	Reasons for not going non NHS	Method of offer non NHS Types non NHS interventions: Alzheimer Society general, Life story (University),Memory cafes (Alzheimer's Society), ==Other (unclear), Service development group.== Singing for brain (Alzheimer's Society), Theatre, Walking group (Alzheimer's Society) Views about PSI offer non NHS

Research involvement	Roles	Self-awareness	Services reported and why
		Differing accounts	Age UK, Alarms, Continence, Crossroads, Domestic, GP, Medication support, Private, Unclear

==Sheltered accommodation==	==Signposting==	Social support networks	Staff qualities (positive/negative)
		Being together, dependence or not	

Timing of intervention offer	Travel & locations	Voluntary work	Wanting stimulation

What else might meet needs	Work history
Emotional support, How to live well with dementia, monitoring / contact, more of the same, more support, respite, care, non AD services for vascular dementia or mild cognitive impairment, nothing really needs met, support to manage work or voluntary work, wanting strategies)	

<u>Additional codes identified only for transcripts from joint interviews</u> (about people with dementia expressing themselves within a joint interview)

- FM leading - example of where in the joint interview the family member answers for the person or leads
- PWD own view - example of person with dementia expressing own view, within the joint interview

<u>Additional codes identified for researcher reflections</u>

- Active aging: post-interview and reflections about the aging process
- Alzheimer's Society & NHS - my thoughts about the differences, similarities or links between the two
- Boundaries researcher-clinicians -my thoughts about me as OT / the OT role vs. as a researcher
- Challenges interviewing- examples of when I say how I found it difficult to keep people on track , e.g. to prompt, to steer
- Dynamics of joint interviews - my thoughts about the dynamic of different people talking within the interview and how this affected trying to get the person with dementia's perspective
- Implications - my thoughts about potential implications for services or research
- Living alone - my thoughts about the impact of person living alone
- Methods - my thoughts on the methods I used / study design
- Engagement - my thoughts about what had helped or hindered engagement
- Pathways for non-AD - my thoughts about apparent lack of interventions for people with non-Alzheimer Disease type dementias
- People being upset - my thoughts about when people became upset in interview
- Using 'd' word - my reflections about using word dementia in the interview/research process
- Whose reality / awareness - my reflections about considering whose reality I am representing, issues of awareness/ self-awareness, accounts of dementia / situation

Appendix 3.23.6 Candidate themes for solo and joint interviews with people dementia and family members, with codes that informed them

Candidate theme 1: Awareness, adjustment, acceptance
Codes
Impairments symptoms and impact, Independence, PADL DADL, isolation, Being alone, Vulnerability, Risk, Naming it, Self-awareness, Differing accounts
Candidate theme 2: Intervention appeal (fit, perception of benefit, qualities of the intervention)
Codes
Group dynamics, Personality, joining, willing to try, Reasons for not going (travel, enough on, Forgot, no offers, weather), Reports of intervention non NHS NOT engaged with (Reasons for not going, Staff qualities positive/negative) Timing of intervention offer Views about intervention offer non NHS, Views about intervention offers, Reasons for going, Views re hypothetical offers, Wanting stimulation
Candidate theme 3: Past experiences and active lives
Codes
Community activities and personal interests, Dementia experience, Causes of dementia, Dementia medications, Diagnosis journey, Diagnosis to tell or not, Impairments symptoms and impact, Stigma examples, Naming it, Knowing others with dementia, Research involvement, Roles, Voluntary work, Work history
Candidate theme 4: Services, context
Codes
Descriptions Non NHS intervention (Alzheimer Society run general, Memory services general, Method of offer non NHS intervention), NO offer due to type of dementia/cognitive impairment, Reports of PSI NHS-offers & engagement, Descriptions of interventions (Method of offer, Types of NHS intervention, CST, Info sessions, Exercise group, Social support), Research involvement, Signposting, Types non NHS PSI, Life story work, Memory cafes, Other, Service development group, Singing for brain, Theatre, cinema, Walking group)
Candidate theme 5: Trust, relationships, fear, anxiety
Codes
Mood issues (Anger, anxiety, worry, motivation, suicidal thoughts), Social support networks Together, dependence or not

Candidate theme 6: Practicalities
Codes
Practicalities of sessions, Travel & locations

Candidate theme 7: WHAT ELSE MIGHT MEET NEEDS (including what people said about How to live well with dementia & what they would advise others living with dementia)
Codes
What else might meet needs (emotional support, how to live well with dementia, more monitoring / contact, more of the same, more support, respite, care, non AD services for vascular dementia or mild cognitive impairment, nothing really needs met, support to manage work or voluntary work, wanting strategies)

Appendix 3.23.7 Reviewed themes, final key themes and subthemes for solo and joint interviews with people with dementia and family members

Reviewed themes	Final key themes and subthemes	
Reviewed Theme 1: Adjustment	**Theme 1**	**Adjusting to life after a diagnosis**
	Subtheme	Self-awareness and differing accounts of dementia
Reviewed Theme 2: Intervention appeal, perception of benefit	**Theme 2**	**Appeal of interventions and perception of benefit**
	Subtheme	Personal narratives
	Subtheme	Mixing with others with dementia
Reviewed Theme 3: Service context, the offer	**Theme 3**	**The service context**
	Subtheme	Signposting
	Subtheme	Practicalities: timing, location, travel and venues
	Theme 4	**Relationships**
	Subtheme	Encouragement and persuasion
	Subtheme	Managing fear and anxiety
Reviewed Theme 4: unmet need and suggestions for living well	**Theme 5**	**Unmet needs and suggestions for services**
	Subtheme	Living as well as possible with dementia

Appendix 3.23.8 Initial codes applied to transcripts from staff interviews

Dementia	Engaging with interventions over time	Influences on staff referring, offering	Main influence summary (what would you say main influence is?)
Severity, Variability, Stigma		Consent, Choice, Services wider context, staff communication, staff responses to declining the offer	

Memory services pathway	Driving	Medication	Overloading people
Process up to diagnosis, Referral pathway, Process at diagnosis, Process post diagnosis			

Record keeping re: interventions	Resources	Trust, rapport	Unmet needs and how to meet

Vascular dementia	Descriptions of & reasons for uptake or decline
	Age as factor, Awareness acceptance, Being alone, Independence, Class, education, Continence, Cultural influences, Family role, Fear anxiety worry, Feeling a burden, Feeling fine early stage, Group dynamic being a mixer, Group dynamics other, Length of course or sessions, Location of sessions, Medication, Mixing with others with dementia, Mobility issues, Motivation, Initiation, Physical health issues, Previous experience of services or groups, Too much on, Transport & travel

Interventions offered (context of)	What interventions are offered
When intervention offered, Who offers intervention, Who provides intervention	Alzheimer's Society, CBT, Cognitive rehab., CST, Education information group, Interventions only for family carers, Memory cafes, Exercise group, Occupational Therapy, Other services, Signposting, Singing for brain

<u>Additional codes used for reflections applied to transcripts from staff interviews</u>

- Alzheimer's Society vs. NHS – my thoughts about how they compare
- CST reflections– my thoughts about CST
- How to work with people declining – my thoughts about challenges of working with those who decline services/offers
- Importance of language
- Methods – my thoughts about the impact of methods used in interview
- Challenges of interviews
- OT researcher hats - thoughts about my role as OT or researcher and possible impact
- PSI definition – my thoughts about terminology / definition of psychosocial interventions
- Service context – my thoughts about service context
- Engagement- my thoughts about what may influence uptake of offers, initial engagement

Appendix 3.23.9 Candidate themes for transcripts of staff interviews with codes that informed them

Candidate theme 1: external influences, service related (*Factors that staff talked about as influencing uptake that seemed to do with the service context, service issues)*
Codes
Length of course / sessions, Location of sessions, Memory services pathway and referrals pathway, Process up to diagnosis, Process at diagnosis, Process post diagnosis, Driving, Medication, Interventions offered in what context, Record keeping re interventions, Resources, Services wider context, Transport & travel, What interventions are offered (CBT, Cognitive rehab., CST, Education information group, Family member only, Memory cafes, Exercise groups, OT, Other services, Signposting, Singing for brain) When interventions are offered, Who offers, Who provides, Overloading of information
Candidate theme 2: interaction and communication (*Factors staff talked about as influencing uptake that were to do with the interaction between the service users and staff members)*
Codes
Consent & choice, Staff communication, Staff responses to decline, the offer process, Trust & rapport
Candidate theme 3: Internal to person with dementia & family member (*Influences staff talked about that were do with the person with dementia and/or family member)*
Codes
Age as factor, Awareness & acceptance, Being alone, Independence, Class & education, Continence, Cultural influences, Dementia severity, Dementia variability, Family member role, Fear anxiety worry, Feeling a burden, Feeling fine early stage, Group dynamic (being a mixer, other), Medication, Mixing with others with dementia, Mobility issues Motivation & initiation, physical health issues, Previous experience of services or groups Too much on, Vascular dementia
Candidate theme 4: Unmet need (*Unmet needs and suggestions about how to meet them)*
Codes
Unmet needs & how to meet them

NB: stigma not included in candidate themes

Appendix 3.23.10 Reviewed themes and final key themes and subthemes for staff interviews

Reviewed themes	Final key themes and subthemes	
Reviewed Theme1 External influences: service context and wider society	**Theme 1**	**Context: service contexts and wider society**
	Subtheme	*Different types intervention to encourage engagement with services*
	Subtheme	*Accessing interventions and practicalities*
	Subtheme	*Sociocultural influences*
Reviewed Theme 2 Individual characteristics as influences on uptake	**Theme 2**	**Individual characteristics**
	Subtheme	*Impacts of dementia on individuals*
	Subtheme	*Individual personality and personal background*
	Subtheme	*Pivotal influence of family members*
Reviewed Theme 3: How the offer is made: communication and relationships between staff and people with dementia	**Theme 3**	**Communication and relationships**
	Subtheme	*Respecting personal choice and consent*
Reviewed Theme 4: Unmet need	**Theme 4**	**Unmet need and ideas for service development**

Appendix 3.24 Summary of data triangulation process

Step	Description of process (158) (p.383)	How adapted and applied in this study
1) Sorting	Sort findings from each data source or method into similar categorised segments that address the research question to determine areas of content overlap and divergence	- Coding and thematic analysis completed for each data set separately - Contents of both reviewed to identify key themes within each data set to create a unified list of themes - This list then used to compare for presence and frequency, meaning and examples - These themes used to form rows of a convergence coding matrix summarising similarities and differences between the two data sets[1]
2) Convergence coding	Identify themes from each data source. Compare findings to determine degree of convergence i) essence of the meaning and prominence of the themes ii) coverage and examples in relation to each theme. Apply convergence coding scheme: Agreement: full agreement between both sets of findings on both elements of comparison (e.g. meaning, prominence, coverage are the same) Partial agreement: agreement on one but not both components (meaning or prominence of themes are the same or coverage and specific examples are the same) Silence: one set of findings covers the theme, whereas the other set of findings is silent on the theme or example Dissonance: disagreement between the sets of findings on both elements of comparison (meaning and prominence are different, coverage and examples are different)	- The two sets of findings compared, looking for similarities and differences in i) meanings and interpretation of themes ii) frequency and prominence of themes i.e. number of transcripts mentioning topics related to a theme were identified - Results from applying convergence coding scheme were included in the matrix with example quotes from each set of findings
3) Convergence assessment	Review compared segments to provide global assessment of level of convergence Document where researchers have different perspectives on this	Reviewed level of agreement across themes for both data sets ; one researcher (myself) competed this exercise
4) Completeness assessment	Compare nature and scope of the unique topic areas for each data source to enhance completeness of the united set findings and identify key differences in scope and/or coverage	- Reviewed and compared each theme in each data set, examined example quotes - Identified overarching themes across both data sets - Primacy given to themes identified from interviews with people with dementia and family members themes; these themes used to examine how themes identified from interviews with staff converged or diverged - Looked for examples that did not fit overarching themes

Step	Description of process (158) (p.383)	How adapted and applied in this study
5) Researcher comparison	Compare convergence or dissonance and completeness of the united findings among multiple researchers to identify agreement or disagreements.	Not done as only one researcher (myself) competed this exercise
6) Feedback	Feedback of triangulated results to research team and/or stakeholders for review and clarification	Triangulated results fed back to supervisors and edited in response; Participant validation considered, decision made not this was not feasible or appropriate for this study

Appendix 3.25 Lay summary sent to participants with dementia and family members

You very kindly took part in an interview for this research study between December 2017-May 2018. This is a summary of the main findings.

A study to explore how people with early dementia respond to offers of support and services: feedback of key findings

What was the aim of this study?

To improve understanding about why people with early dementia may accept or reject services and support offered after diagnosis.

Key findings

Who took part?

16 people with early dementia, over 65 years old, diagnosed with dementia within the last two years and living in the community were interviewed – four people were interviewed alone, 12 with a family member. Also, 12 staff participated.

What support and services did you and others describe?

You and other people mostly talked about participating in or declining:

- cognitive stimulation therapy groups and education and information groups
- memory cafes and 'Singing for the Brain'

Key messages

➢ Responses to offers of support and services were influenced by individual responses to diagnosis, experiences of dementia and services.

➢ Adjusting to dementia and acknowledgement of the diagnosis affected whether people felt they needed support or not.

➢ If activities offered appealed and people perceived a potential benefit to participating, people accepted offers of group activities.

➢ Groups which offered social contact, peer support, information, enjoyable activities and mental stimulation were valued. But, groups did not appeal to all.

➢ Activities aimed specifically at people with dementia also did not appeal to all.

➢ Continuing with community-based activities was valued.

➢ Ability to travel and convenience of locations greatly influenced whether people participated.

➢ Stigma seemed to discourage some people from accepting support or activities offered.

➢ Families provided emotional and practical support, both were vital to acceptance of services.

➢ Trusting relationships between people with dementia, family carers and staff encouraged acceptance.

Here are some quotes to illustrate some of these issues

(NB: pseudonyms used)

"..I don't really feel any different... some days I do get more forgetful, but I don't think I suffer so much from that do I?.... You're the one that notices this more than me..." George (living with dementia)

"... I know there's a walking group...but I don't know really about that... how far down the line they would be with their Alzheimer's? I'd want to be able to go and just converse with somebody who's able to, you know." Beryl (living with dementia)

"Yeah because that's the only reason that they are wanting me to go to these places, is to assess me and put me away. My John says there's no way you are going to be locked away" Jimmy (living with dementia)

"The crunch is it's got to be something that drives the brain... if you don't it's goodbye Vienna, you can't pull it back, and it tries to drift ...." Keith (living with dementia)

Why was this study important?

- Health policy promotes 'living well' with dementia.
- NHS dementia services are encouraged to provide support and activities for people after diagnosis. This is because evidence suggests that engaging in activities can help improve thinking skills (like memory or concentration), independence with everyday tasks, quality of life and how carers cope.
- However, what influences people with early dementia to accept offers of support or services is poorly understood and little research about this topic exists.
- It is hoped findings from this study can contribute to the evidence about support services for people with early dementia, after diagnosis.

Services offering support for people with dementia and researchers should:

- Identify what type of support is offered to people specifically with early dementia after diagnosis, where and when.
- Identify key characteristics of those who reject offers of support or services (such as age, gender, the type of carer a person has or if they live without regular support from another person, type of dementia or post code).
- Examine reasons for acceptance or rejection of support offered by services.

This is because identifying who rejects support and why could inform service developments.

- Support people with early dementia engage in activities they wish to do, which may be in the community or not only involve groups aimed exclusively at people with dementia.
- Consider venues, location, ease of travel and whether transport provision or support is possible when planning activities. Familiar, community based venues may encourage uptake.

Actively involve people with early dementia and families in designing services to meet their needs and preferences for support after diagnosis.

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Appendix 3.26 Executive summary sent to staff participants

A study to explore take up of psychosocial interventions for early stage dementia -

A summary of findings for staff and services

Study aim: To enhance understanding about the uptake of psychosocial interventions for people with early dementia and their family carers.

Why is this study important?

Health policy promotes 'living well' with dementia and memory services are encouraged by the Memory Services National Accreditation Programme to provide psychosocial interventions after diagnosis. NICE guidelines also recommend group cognitive stimulation therapy (CST) for people with mild to moderate dementia and suggest that services consider offering group reminiscence therapy, cognitive rehabilitation or occupational therapy and a range of activities to promote wellbeing tailored to a person's preferences. This is because evidence suggests that psychosocial interventions can maintain or improve cognitive skills, independence with daily tasks, quality of life and carer coping. However, what influences people with early dementia to accept psychosocial interventions is poorly understood and little research about this topic exists. Findings from this study can contribute to the evidence about psychosocial interventions for people with early dementia after diagnosis.

How was this study conducted?

- People with early dementia, family carers and staff were recruited via two NHS memory services, a local branch of the Alzheimer's Society or 'Join Dementia Research' online research register.
- People with dementia were over 65, described as living with early dementia, diagnosed within the last two years and living in the community. They had capacity to consent to the study and participate in an interview. Semi-structured face-to-face interviews were held with people with dementia alone or jointly with a family member if wished. Verbal, written and visual prompts were used during interviews to support communication if needed.
- Staff were interviewed face-to-face or by telephone and one focus group was held.
- All interviews were audio-recorded and transcribed. Thematic analysis identified key themes. Triangulation was used to integrate findings from the different kinds of interviews and participants.
- Ethical approval (IRAS ID 227380, REC Reference 17/NW/0414) was obtained.

KEY FINDINGS

Who took part?

- ➢ Sixteen people with early dementia and 15 family carers
- ➢ Twelve staff (three nurses, three occupational therapists, two service managers, one psychologist, one doctor, two support workers)

People with dementia and family carers mostly discussed group CST, education and information groups, memory cafes and 'Singing for the Brain'. Staff also mostly discussed these interventions but some also talked about cognitive rehabilitation, psychology and occupational therapy. Five key themes about influences on acceptance or rejection of psychosocial interventions by people with early dementia were identified. These were:

1) Adjusting to dementia and self-awareness
2) Appeal of interventions and perceived benefit
3) Context of services and stigma
4) Relationships and trust
5) Unmet needs and suggestions for services

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Key messages from this study are:

- Acceptance or rejection of interventions was influenced by individual responses to diagnosis, experiences of dementia and dementia services.
- Self-awareness and adjustment affected whether people felt they needed interventions or not.
- If activities involved in interventions appealed and a potential benefit to participating was perceived, this positively influenced uptake.
- Interventions offering social contact, peer support, information, enjoyable activities and mental stimulation were valued.
- Group interventions did not appeal to all, nor did interventions specifically aimed at people with dementia.
- Continuing with community-based activities was valued.
- Ability to travel and convenience of locations greatly influenced uptake.
- Stigma seemed to discourage some from accepting interventions.
- Emotional and practical support from family carers was vital to acceptance of interventions. Trusting relationships between people with dementia, family carers and staff appeared important facilitators of acceptance.

Recommendations

Services for people affected by dementia should carry out audit or service evaluations to:
- Identify what kinds of interventions are offered to people with early dementia, when and where.
- Identify key characteristics (e.g. age, gender, caring relationships, living situation, postcode, ethnicity, type of diagnosis) of those who reject or accept interventions.
- Examine reasons for acceptance or rejection of interventions in practice.
- Examine whether tailored support to address individual needs and goals (for example, those related to social participation and quality of life, as well as safety and risk) in addition to group work are offered to people with early dementia who may need support to continue to engage with valued activities.

    Such audits or evaluations could help identify areas for service development.

Services for people affected by dementia should consider:
- The need for tailored support to enable people with early dementia to remain engaged in their communities and lives.
- Awareness raising to continue to address stigma associated with dementia and supporting dementia 'friendly' or dementia aware approaches so that interventions offered in communities can be inclusive for those with early dementia.
- Venues, location, ease of travel and whether transport provision or support is possible. Familiar, community based venues may encourage uptake.
- Reviewing referral pathways for those with early dementia who may have been working (paid or voluntary) at time of diagnosis but are over 65, those struggling to adjust emotionally after diagnosis, and those who may have specific needs such as minority ethnic backgrounds or LGBTQ+ people with dementia or people with different types of dementia diagnoses.
- Consider how people with early dementia who live without regular support of another person can be supported to engage with services and interventions.

Involving people with early dementia and carers over 65 locally in designing services to support people after diagnosis
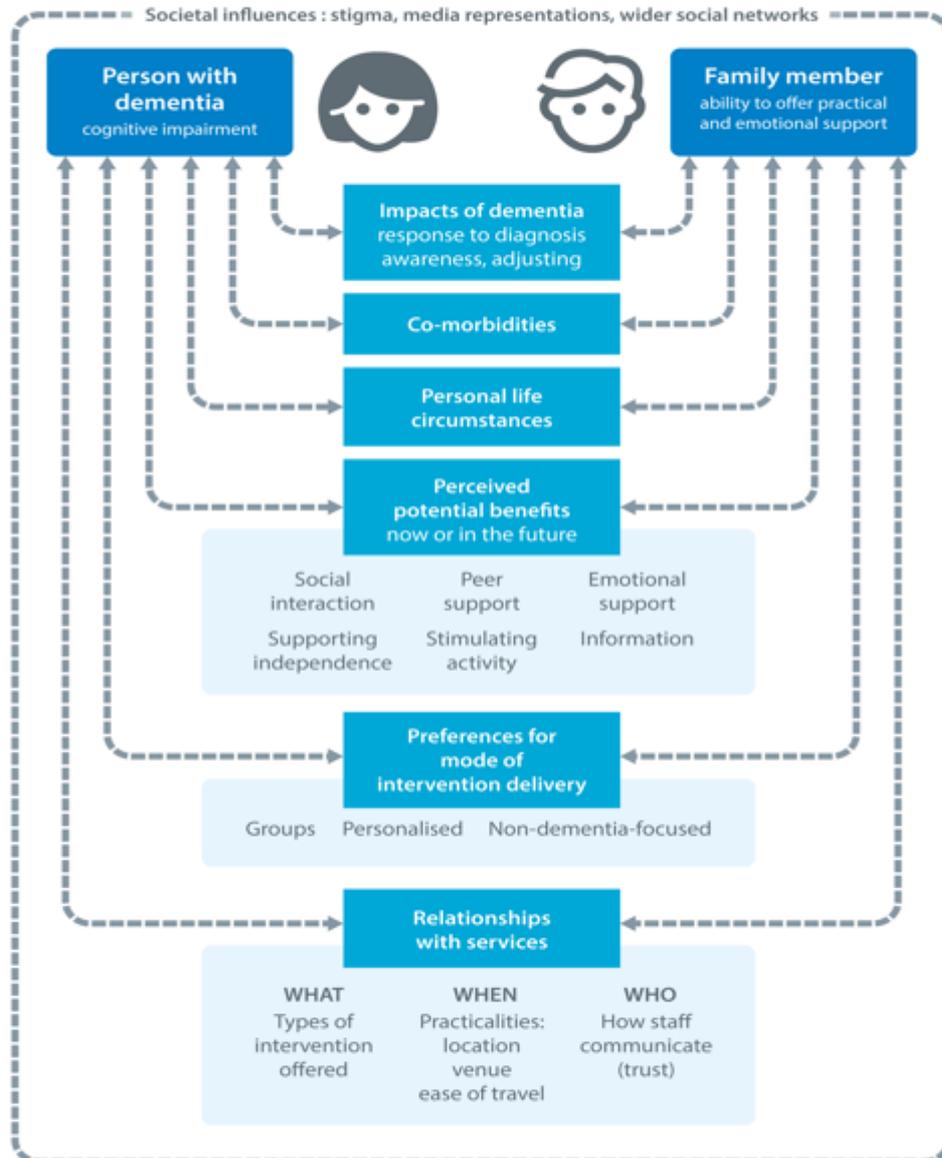
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The following are some quotes to illustrate the key themes

Theme 1: Adjusting & self-awareness

"..I don't really feel any different... some days I do get more forgetful, but I don't think I suffer so much from that do I?..... You're the one that notices this more than me...."George (living with dementia)

"I think a lot of people don't think they have dementia...even when they've been to the consultant, and they've had a diagnosis...[and] come for a post diagnosis appointment.....so tell them to go along to a group for somebody with a memory problem; 'well I don't have one so I wouldn't need that group'" Nurse (focus group)

Theme 2: Appeal of interventions & perception of benefit

"... I know there's a walking group...but I don't know really about that... how far down the line they would be with their Alzheimer's? I'd want to be able to go and just converse with somebody who's able to, you know." Beryl (living with dementia)

"The crunch is it's got to be something that drives the brain... if you don't it's goodbye Vienna, you can't pull it back, and it tries to drift ...." Keith (living with dementia)

Theme 3: Context of services & stigma

"...at the memory clinic they overwhelm you with information and invite you to all these things... oh I can't even think about what there were. ... I think they throw everything at you, in less than an hour or something..." Linda (wife)

"..... 6 week target to diagnose....So all the resources get directed there...the way the service is measured...to the commissioners is on how many people we're getting diagnosed, not on what happens afterwards....So whilst that's been driving it...we've been saying, 'well do you know what, what about when people do get diagnosed what are we offering that's of any benefit?....." Psychologist

"As long as they [relatives] don't mind...I couldn't go on me own I don't think because I'd have to catch a bus and then get a taxi..." Mavis (living with dementia)

" [we]...don't provide transport...that can cause anxiety...and it does depend whether someone's got a carer that can actually bring them along" OT (focus group)

"Yeah because that's the only reason that they are wanting me to go to these places, is to assess me and put me away. My John says there's no way you are going to be locked away" Jimmy (living with dementia)

Theme 4: Relationships & trust

"I didn't want to go into a home ... Jimmy (living with dementia)

"We had to ask [Staff name]...[to] explain ... we weren't taking him to keep him, it was for an assessment to see if the courses...were going to help...after [Staff member} spoke to him... he knew he wasn't staying, so he were like...from shuffling his feet...to a proper spring in his step ...when we said about going back...couldn't get him back in the car quick enough..." John (son-in-law)

NB: pseudonyms used

This diagram summarises the main findings from this PhD study about influences on acceptance or rejection of psychosocial interventions by people with early dementia living in the community, after diagnosis NB: *This diagram is based on findings from the interviews as well as two literature reviews conducted in 2016 and 2019*

Societal influences : stigma, media representations, wider social networks

Person with dementia
cognitive impairment

Family member
ability to offer practical and emotional support

Impacts of dementia
response to diagnosis
awareness, adjusting

Co-morbidities

Personal life circumstances

Perceived potential benefits
now or in the future

| Social interaction | Peer support | Emotional support |
| Supporting independence | Stimulating activity | Information |

Preferences for mode of intervention delivery

Groups Personalised Non-dementia-focused

Relationships with services

| WHAT | WHEN | WHO |
| Types of intervention offered | Practicalities: location venue ease of travel | How staff communicate (trust) |

Pen portraits: Tom and Sally

Tom (81 years) was diagnosed with Alzheimer's Disease about two years ago. He was interviewed with his partner Sally (69 years), also retired. They lived together in a terraced house in a city.

History of diagnosis: Tom said it was his son who encouraged him to see his GP initially, and that when the GP did various tests it became clear to Tom he could not give the expected answers. From there he was referred to memory services, and after more testing was given a diagnosis of Alzheimer's.

Co-morbidities: Tom said his mobility was poor and he had glaucoma and systemic sclerosis.

Acknowledgement of diagnosis and awareness of changes: Tom acknowledged he has dementia. He said it's difficult to remember certain things but that he makes his own decisions.

Personal interests and activities: Tom spends his time gardening and managing his investments online on his PC. They visit a relative with Parkinson's and dementia each week. Tom and Sally said they do most activities together. They try to walk most days, and go into town by bus at least once a week. Tom misses driving, listening to live jazz and cycling. He recently tried cycling again with his son in the park and really enjoyed it. They have looked into somewhere to listen to live jazz but do not want to go out in the evening or to busy pubs.

Social support networks: Tom's son lives close by, they see him quite often and he supports Tom with his IT/PC work, particularly managing passwords for different accounts

Interventions and services discussed: Sally said at diagnosis they were given a large pack of information, and soon after were invited by letter to attend some sessions at memory services about learning to live with memory problems and how to get help with tax, benefits etc, and other support services. Sally said Tom had attended a CST group at memory services and when he came out he seemed stimulated, chatty and happy. Tom, when asked about this group, pulled a face. He seemed ambivalent; he said he did not like the singing, that he would not usually talk to those people and had other things to do. But, when asked, he said he was happy to go again, and that he liked the coffee. Sally said she thought it was good for both of them to mix with other people and get out of the house. She said they would not refuse any invitations for similar interventions and would like a regular suitable commitment or activity.

Pen Portraits: Edith (Liz and Colin)

Edith (87 years) was retired and diagnosed with Alzheimer's Disease 10 months before interview. Edith was interviewed alone first, then with Liz, (62 years) her daughter-in-law, recently retired and her son Colin (64 years) also retired. Edith lived alone but in sheltered accommodation.

History of diagnosis: Prior to receiving a diagnosis of AD, Edith was diagnosed with 'vascular degeneration' and was discharged from memory services, with no support or information. They went back to the GP as they felt Edith's memory and abilities were still deteriorating and said they had to persuade the GP to re-refer Edith to memory services.

Co-morbidities: Edith had arthritis which makes doing the sewing and piano too difficult.

Acknowledgement of diagnosis and awareness of changes: Edith acknowledged her memory and her attention had deteriorated but did not use the word dementia or Alzheimer's herself, saying 'I am alright, but when it comes to knowing where I am and what's going on….".

Personal interests and activities: Edith talked about how much she has always loved dancing and singing and playing piano. She had been a Women's Institute member, icing cakes, flower arranging, quilting and sewing. She said still paints cards. Edith attends church regularly and goes out most days for lunch independently to a local café close to her accommodation. She is known by the staff there and this is now the only place she goes alone. Edith talked about some issues which seemed to make her feel quite anxious. She explained she ruminates about her neighbours and having to do her laundry in the shared facilities, which kept her awake at night.

Social support networks: Edith talked about her appreciation of Liz's support, taking her to places and organising activities for her.

Interventions and services discussed: Edith had attended group CST at memory services each week (which was now finished) and now attended a maintenance CST group monthly at memory services, a Singing for the Brain session each week where she said she had a dance partner and really enjoyed this. She also attends a weekly 'crafty café' in the community, where she chats and plays dominos. Edith is driven to intervention groups by Liz, stays at the groups alone, and is collected. Liz and Colin said they had received a lot of signposting information at the post-diagnosis appointment at memory services and CST group, which led to them finding out about these groups. They had also been signposted to attendance allowance and a charity which provided free of charge daily visits to Edith to help her stay at home, which they felt had been very helpful. They said they knew that Edith would enjoy attending all these groups, as she had always been a sociable person. Liz has noticed Edith no longer says she is lonely, which she used to. Liz said going forward they may need to think about how to support Edith with personal care. Edith said she was content with the amount of activities she does.

Pen portraits: Pam and Dave

Pam (66 years) was retired. Her husband Dave (64) was also retired on medical grounds due to back pain. They lived together in a terraced house in a small town. Pam was diagnosed with frontal temporal dementia and epilepsy about two years before the interview.

History of diagnosis: Dave talked about how Pam's behaviour had changed and this had led to seeking a diagnosis. For example, she would put the wrong things in the oven, buy different things to what they had agreed, which she would never have done before. Getting a diagnosis had taken several months and involved seeing a specialist consultant at a hospital in a different town.

Co-morbidities: Epilepsy and falls. Pam's current epilepsy medication often made her sleepy.

Acknowledgement of diagnosis and awareness of changes: When asked how her life had changed since diagnosis, Pam said 'I have to stop in a lot more'. Dave said Pam's behaviour could be inappropriate at times and was unlike her previous behaviour. For example, telling a stranger an outfit did not suit her or stopping to listen closely to someone else's conversation on the street. When Dave recounted such events, Pam giggled. She didn't talk explicitly about having dementia herself, but said she had worked with people with Alzheimer's, so felt she knew what to expect.

Personal interests and activities: They walked the dog every day. They looked after their grandchildren before school and two days a week after school. Dave does most of the domestic tasks now.

Social support networks: They talked about their son and partner living close by and bringing them frozen meals for the microwave. Dave also said they were seeing less of family given Pam's behaviour could be strange.

Interventions and services discussed: After diagnosis Pam and Dave said they were invited by letter to a CST group at memory services which they attended together. Pam had also attended an exercise group at memory services. They had been to a memory café a few times, but didn't often go as it clashed with their 'free' day when they did not have the grandchildren and liked to get out or go into town. Pam said she had enjoyed the CST group, it had been fun and she liked meeting people the same as her. They had been invited to the maintenance CST group at memory services, which they planned to attend. Dave had attended a carers group run by the Alzheimer's society and also talked about attending a carers group at memory services, whilst Pam and others with dementia did craft activities in another room. Dave talked about how he liked the groups at memory services, as they weren't stuffy and he felt at ease. Dave was keen to engage in services offered, Pam said she would try other groups.

Pen portraits: June and Sarah

June (78 years) was retired and was interviewed with her daughter Sarah (51 years). Sarah worked full time in a professional job. June lived with Sarah and her adult grandson in Sarah's home. They lived in a terraced house in a city. June was diagnosed with Alzheimer's Disease about one year before interview.

History of diagnosis: June and Sarah both talked about how Sarah had noticed changes in June's memory so they went to the doctor. June said she thought if Sarah was saying it, it must be true, even though she herself had not been aware at that point.

Co-morbidities: June was registered blind due to macular degeneration, with Charles Bonnet syndrome, which gives June visual hallucinations. She had limited mobility due to knee and ankle problems, and an underactive thyroid. June was essentially housebound, she could walk a short distance to a neighbour's house if she needed.

Acknowledgement of diagnosis and awareness of changes: June acknowledged she has dementia.

Personal interests and activities: June spent most days were spent at home with the TV on. June was going on holiday abroad soon after the interview, to stay with her other daughter and would fly independently being taken to and met at the airport.

Social support networks: Sarah works full time. If Sarah has to go away, her son will phone his grandma during the day to check she is OK.

Interventions and services discussed: June had no recall of being offered any psychosocial interventions. Sarah was clear they had been given information about memory cafes and intervention groups available at memory services soon after diagnosis but at that point June was 'not bothered'. They both talked about June previously attending a group for people with sight loss but that she had not enjoyed it and not returned. Sarah said she thought June didn't want to be defined by dementia, or sight loss, and just wanted to chat and socialise. June agreed.

Sarah was worried that June was forgetting to eat or was not motivated to do so. Sarah wanted to find a lunch club for her mum and felt she would just arrange it as she felt her mum needed this now. Sarah wished there was a service that could call in on June in the day, just to check she had eaten and have a chat, when Sarah was working all day or away. Also, in order for June to attend that any club or activity, she would need help to get in and out of the house and any buildings so she did not fall June initially said she would not want to go a group where people talk about their feelings, or their illness, but later on in the interview also said she would like to meet others in similar situations.

Pen portraits: Steve and Jan

Steve (70 years) was retired. He was interviewed with his wife Jan (70 years), also retired. Steve was diagnosed with Alzheimer's Disease between three to four months before interview. They lived together in a terraced house in a village.

History of diagnosis: When I first spoke to Steve, he said he was not sure he had dementia as they were still going through the process but when I spoke to Jan she confirmed he had been diagnosed. They described going to memory services for four years prior to diagnosis, and Steve says he did the same tests each time but that he was stable. The last time they went Jan said he was sent for a scan and was given a diagnosis of Alzheimer's Disease.

Co-morbidities: Steve had type 2 diabetes.

Acknowledgement of diagnosis and awareness of changes: Steve acknowledged the diagnosis and that memory difficulties. He said he struggles sometimes to recall words or recent events, forgets what he needs at the shops or what he has just read. Jan says he does not remember what people have just told him. They both talked about how Steve could become very frustrated at times e.g. when trying to remember or find something, he has hit out at the wall or door and cried on occasion because of this. They both felt this was a big change in behaviour and personality for Steve as he would he would not have done this before. Steve's account of his dementia related to an accident where he described taking a knock to the head many years previously, he felt that was when his memory problems started but Jan did not have the seem to share the same understanding of this.

Personal interests and activities: Steve talked about how he has always loved vehicles and mechanics, and reading about these subjects. Steve spent his time tinkering in his shed, going out on his motorbike or reading. They had travelled frequently in their retirement. They talked about socialising quite a lot, having friends over, going to their houses or out for meals.

Social support networks: They both talked about having a large network of family and friends and both had children from previous marriages.

Interventions and services discussed: Steve did not recall being offered any interventions after diagnosis. Jan said they were telephoned by someone from memory services who has invited them to attend a CST group. She said she was unsure what Steve would make of it. Steve said he was not keen but would give it a go because he was willing to give anything a go, at least once. He said he did not like sitting around talking, or having to write or draw, that he liked doing things, like a 'bloke'. He described himself as not keen on groups, but also said that he might learn something from others in similar situations. Jan said she felt maybe the CST group was a bit early for them, she thought he was doing fine, and they were just getting used to the diagnosis but they were both going to give it a go. *NB: When I attended a CST group about a month later aiming to recruit other participants, they were there, so had attended and attended more than once.*

Pen portrait: Keith

Keith (72 years) was retired. I interviewed Keith alone. Keith's wife had died a few years ago. He said he was diagnosed with mixed type dementia about 14 months before interview. He lived alone in a terraced house in a suburban area.

History of diagnosis: Keith did not talk about the process or history of his dementia diagnosis.

Co-morbidities: Keith described a history of falls and his upper limbs shook noticeably, which he also discussed.

Acknowledgement of diagnosis and awareness of changes: Keith acknowledged the diagnosis of dementia.

Personal interests and activities: Keith drives and does his own cooking and shopping. When he was not attending groups run the Alzheimer's Society, Keith said he looks after his house and goes to watch the football regularly.

Social support networks: Keith said he takes his brother-in-law to appointments at memory services. Keith had two children who do not live in the same town as him and he said he does not see them often.

Interventions and services discussed: Keith drives himself to and said he regularly attends Alzheimer's Society groups and most of the memory cafes. He talked about one group being a mix of men and women and being a monthly session. Keith said he had attended a group at memory services where information about benefits and finances was given. He also described attending another group there when no one else turned up. He said staff had said they would contact him about another group at some point. He talked about attending memory cafes and a role he had there in supporting others. He particularly liked one memory café as they played chess and billiards and did activities when there, whereas he described the other memory cafes as being more like a coffee stop and talking.

Pen portrait: Sue

Sue (80 years) was retired, diagnosed with Alzheimer's Disease about a year before interview.

History of diagnosis: When Sue described being given a diagnosis she said it had been about six years ago. However, her son had helped her complete the permission to contact form when I had met them at memory services and memory services staff reported she had been diagnosed about year before interview.

Co-morbidities: Sue described a history of falls and that she had a bleed on the brain about six years ago. The way she talked about this implied there may be some residual tumour or damage, but she explained how it had been decided that they would not to operate. Sue also described heart problems, asthma, rheumatism and that she had four hip replacement operations and two shoulder operations. She also reported macular degeneration. Sue wears an alarm round her neck at home.

Acknowledgement of diagnosis and awareness of changes: When I asked Sue about how things had been since being diagnosed with dementia she said she did not want to acknowledge it and talked about the things she could still do.

Personal interests and activities: Sue talked a lot about her family who were very important to her. Her son lived locally and visited most days. She had several grandchildren. Her daughter also lived close by but worked full time.

Sue said she used like embroidery but finds her sight makes this difficult. She also said she does not go out alone now as she worries about falling, she feels 'funny' and faints. Sue said she has someone help with the garden and her children hoover for her as she bending is difficult. She said she was thinking of getting someone in to help clean. Sue talked about being a member of a local pensioner's club which she joined when she retired, before the diagnosis of dementia. She is the treasurer for this group, although she talked how she wanted to give this up as she been in hospital too many times and worries about taking the money up to the bank and falling. She talked about the activities she does part of this group, for example bingo and dancing, although she does not dance anymore she said she enjoys watching. She also described the trips away they had had and had planned. She had a four day trip away to the seaside planned, staying in a hotel with this group. She said sees friends and goes out for meals with her son regularly. On Saturdays her and two friends go for coffee and shopping. Some Saturday evenings she will go out to the local club, driven there and back by friends. When in the house she described doing crocheting, crosswords or watching TV.

Social support networks: Sue said she sees people every day.

Interventions and services discussed: Sue said she attended a weekly CST group at memory services and that her son takes her. She said it was a laugh, that she enjoyed it and that she goes because although she has friends and family she does not see as many people as she used to. So, when memory services suggested it, she said her son said she should go and he would take her, so she agreed to go.

Pen portraits: Dot and Jenny

Dot (84 years) was a retired nurse, diagnosed with mixed type dementia (Alzheimer's and Vascular dementia) within the last year before interview. I interviewed her with her friend and neighbour Jenny (64 years), who previously worked as a carer but was currently unemployed. Dot lived alone in a one bedroom flat in a city. Dot described having moved into the flat relatively recently as she had sold the home she had lived in with her husband, who had had dementia and died (it was unclear when this had happened). Dot says she could 'see him round very corner' and still does sometimes, and she felt she was not coping. She said she then moved in with her daughter, but soon after was asked to leave. Dot was unsure why or what went wrong, but she had previously put her name down for a flat with council and one came up in area she knew.

History of diagnosis: Dot described going to her GP gave her the diagnosis, and has known her and husband for many years. She said once diagnosed she decided to join every activity or group she was offered.

Co-morbidities: Dot described her vision as having taken 'a funny turn', that she had chronic ischemia (heart disease) and renal failure. She had also had a stroke.

Acknowledgement of diagnosis and awareness of changes: Dot acknowledged the diagnosis and talked openly about her memory difficulties and other difficulties such as mobility and balance.

Personal interests and activities: Dot says when she's in the house she needs someone to talk to. Her and Jenny have been working on creating a garden space out back and like going out for lunch or coffee, to town, or to buy plants. Dot cooks and cleans for herself, but talked about often dropping food/spilling things. Dot talked about feeling she was not perhaps able to look after herself totally anymore and was thinking of asking social services for help.

Social support networks: Jenny supported Dot informally, by visiting every morning and every evening.

Interventions and services discussed: Dot said she had attended a six week group at memory services with other people caring for those with dementia (when her husband with dementia was alive). She described attending 'Singing for the brain' and a dementia café, run by the Alzheimer's Society, both monthly. Attending these required a bus trip or taxi. She also talked about going to a weekly quilting/patchwork group at the local library with a friend, going to church weekly and helping with the tea service every fortnight. Dot and Jenny talked about having been on a few coach day trips.

Pen portraits: Mavis and Maureen

Mavis (87 years) was retired. She was diagnosed with mixed type dementia (vascular dementia and Alzheimer's Disease) just under two years before interview. Mavis lives with one her daughters, her son- in-law in a village. She was interviewed with her sister Maureen who lives elsewhere. Maureen was retired and had come to stay with Mavis to look after her whilst both Mavis's daughters were on holiday together.

History of diagnosis: Mavis and Maureen did not discuss the process or history of diagnosis

Co-morbidities: Mavis was hard of hearing and wore hearing aids. Mavis had also what Maureen described as a mini stroke in the last year.

Acknowledgement of diagnosis and awareness of changes: Maureen said how much she and the family felt Mavis had deteriorated in the last year, and that Mavis now slept longer and more often. Maureen said she often had difficulty waking Mavis, although she said Mavis's daughters were better at waking her up than she herself was. Maureen explained that the family talked to Mavis about having memory difficulties rather than using the word dementia. She also explained, when Mavis was in the bathroom, that one of Mavis's sons had died, but that she forgot this and if reminded became very upset. Maureen questioned whether this grief might be a reason for Mavis sleeping so much.

Personal interests and activities: Mavis talked about she used to be in an amateur operatic society and went go to local art classes (until about a year ago) and enjoyed painting at home. Mavis said she does not now go out independently.

Social support networks: Mavis was supported by her daughters and their families to attend interventions.

Interventions and services discussed: Mavis did not recall attending a CST group at memory services until her sister described some of the activities they had done there. Mavis said she was fine about going as long her family could take her and she would be happy to go to groups long as one the family could take her. Maureen said the family were planning to start taking Mavis to 'Singing for the Brain' and Mavis said she would like to go if they could take her.

Pen portraits: Larry and Irene

Larry (77 years) was retired, and had been diagnosed with vascular dementia about 18months before interview. He was interviewed with his wife Irene also retired, who was his carer. They lived in a small town.

History of diagnosis: Irene talked about how when they had been given the diagnosis of vascular dementia once the doctor had seen the scan results they had said they would not see them again, and if they wanted to come back to memory services, they would have to go through the GP. Irene thought they would have monitored Larry.

Co-morbidities: Larry had had a major stroke 13 years ago, and has had several mini strokes since. He also has a kidney tumour and prostate cancer. Larry cannot walk independently and uses a mobility scooter or wheelchair outside. After the stroke he was able to walk short distances, Irene said she felt his mobility and function has deteriorated over time and with age.

Acknowledgement of diagnosis and awareness of changes: When asked about the impact of dementia on his life Larry said it was a disappointment, as he keeps having tumbles if he turns too sharply

Personal interests and activities: Larry's main interest now is the horses, he follows and uses the internet for this and goes into the village independently on his mobility scooter to the betting shop. Irene says he can't remember what he ate yesterday, or use the PC for anything else, but can manage his horses. Irene has been caring for Larry full time since his stroke. Irene said he can't do much now, that he used to do the garden and help around the house but thinks since the dementia, his age and effects of the stroke long term have led to him being able to do less.

Social support networks: They both talked about family and friends who lived locally, and visited regularly. Irene also explained how their children were busy working and with young families. When I was leaving, Irene talked to me at the door about difficulties she had supporting Larry, especially at night when he was often incontinent. This was very demanding for her to manage and said although she felt supported by family and friends she felt this was something people could not help with. Irene had organised an assessment with social services, which was due soon.

Interventions and services discussed: Larry had attended an exercise group for people with dementia at risk of falling, run by memory services. Irene drove and accompanied them there. When I asked Larry about other types of support or activity he might like to try, he said he was happy with what he was doing now and Irene said they were happy to mix with friends and family rather than attend a group.

Pen portrait: Beryl

Beryl (82 years), was retired and interviewed alone. She was diagnosed with Alzheimer's Disease about six months before interview. She lives alone in a house she has lived in for over 50 years. Beryl had lived with her partner of 30 years, who died three years ago.

Beryl had two sons, but she told me one died about 14 years ago.

History of diagnosis: Beryl described that a diagnosis was given after she had started having hallucinations. She was not sure whether these had been the result of dementia or not taking medicines for cystitis. She says she was forgetting to take her medication.

Co-morbidities: Beryl said she had had a transient ischemic attack and suffers with regular sinus and allergy problems.

Acknowledgement of diagnosis and awareness of changes: Beryl acknowledged she has Alzheimer's. Beryl described how she had now put her name down for a sheltered accommodation retirement village after much thought about whether she wanted to move or not, and discussion with her son. She was planning to move there when a place became available.

Personal interests and activities: Beryl said she often meets friends in town for lunch and they walk around the park most days when the weather is OK. Beryl joined a walking group on retirement, used to do local art classes and volunteer for the Samaritans and a homeless charity. Beryl said she would like to do something interesting, meet new people and possibly volunteer. She has been a member of a local choir for the past 10 years, which she really enjoys and wants to keep going with and enjoys classical music.

Social support networks: Beryl lives independently and travels into town independently by bus. She now has a paid care worker visit daily to help her take her medications. Beryl described socialising regularly with friends. She also speaks to friends by telephone regularly. Beryl said she sees family regularly.

Interventions and services discussed: Beryl had attended a Life Story group run by a University. She also talked about going to a group at the Alzheimer's Society that she thought was going to be about apps but turned out to be a group of people talking and who she thought were recently diagnosed. She said she did not this group very much because they were just sitting talking. She also talked about going to 'Signing for the Brain'. Beryl said she was offered a group by memory services but did not go the first time due to the snow, and then forgot to call them. She said she does not feel she needs anything else group wise. She also described wanting to attend a service user form run jointly by a local NHS Trust and the Alzheimer's Society, but she needed to arrange this. Beryl said she had tried a memory café locally but thought it was not for her.

Pen portraits: George and Linda

George (73 years) was retired. He had been diagnosed with Alzheimer's Disease about five months before interview. He was interviewed with his wife Linda (72 years), also retired. They had recently moved from their family home of many years to smaller flat, Linda had talked to me on the telephone before the interview about what an emotional upheaval this had been for them both.

History of diagnosis: Linda had noticed the memory loss as well more physical slowness in George, so they went to the GP who referred him memory services who initially diagnosed mild cognitive impairment. They returned to the GP again a few months later after George had had a few falls. George felt these falls were just because of the steps, but then they were referred to memory services and a diagnosis of AD given. Linda and George talked about when they were given the diagnosis at memory services and how shocked and upset they were, she said the doctor just gave them loads of leaflets and that was it. Linda said they don't like going there, seeing people who are very disabled and as it is near where George used to work. Linda explained they only go for the drugs and to be monitored for that.

Co-morbidities: George described no co-morbidities, other than a major operation a few years ago from which he had recovered. But, they both said George had never quite got his strength and stamina back to the same level since then.

Linda did not report being diagnosed with a mental health condition she described struggling emotionally and feeling anxious, especially since the move.

Acknowledgement of diagnosis and awareness of changes: Linda said George is ashamed of the diagnosis, does not want his former colleagues to know. George acknowledged the diagnosis during interview and also said he wasn't really aware of changes in his memory himself, but that his wife noticed this more than him.

Personal interests and activities: George spent his time playing golf, reading, playing the piano a bit and gardening. He had also been attending a Sporting Memories group at the local library for about the past year. George is still driving, sometimes does the shopping, goes to the gym regularly and takes long walks, follows his local football team and will go to watch them if their son is visiting.

Social support networks: George and Linda described seeing family and friends regularly, but also that they had not told any of them about the diagnosis as yet.

Interventions and services discussed: Linda says they were offered a group at memory services but that they would not be keen on a standard group programme. She said she could see the benefit of George talking one-to-one and how George responds to that. George said he would not be interested in the education and information group they were offered but could be interested to hear an interesting speaker on dementia who could summarise the latest developments. They had attended a 'Singing for the Brain' session. George was not keen initially but said that when he went, the songs were familiar and as other people got up to dance he joined in and actually enjoyed it, surprising himself. Linda said it was wonderful. Linda had phoned the Alzheimer's Society to get advice about attendance allowance. A worker came to see them at home and spent time talking to them, and suggested a few possible activities.

Pen portraits: Jimmy, John and Aida

Jimmy (71 years) and his wife Aida (77 years) were both retired and lived together. Jimmy had been diagnosed with Alzheimer's Disease 11 months before interview. They were interviewed together with their son-in-law John (57 years). John lived close by and had taken early retirement due to ill health. They lived in a village.

History of diagnosis: John described how Aida and Jimmy had not told him and his wife about the changes in Jimmy such as disorientation and memory difficulties initially. Jimmy became tearful recounting being diagnosed and believing this would mean he would be taken away and put into a home.

Co-morbidities: Jimmy had severe glaucoma and was hard of hearing. Also, getting to the toilet on time had been difficult but more recently this was being managed better with medication. John also told me Aida had been diagnosed with anxiety, had poor eyesight and hearing.

Acknowledgement of diagnosis and awareness of changes: Jimmy acknowledged the diagnosis during interview and talked about how worried he had been when noticed changes in himself.

Personal interests and activities: Jimmy and Aida walked in into the village every day and took the bus back if they had a lot to carry. John and his wife often take them to visit familiar places, as they need to know where the toilets are. Jimmy likes to garden, he makes the bed and makes porridge in the morning. His wife lays his clothes out for him, John says Jimmy needs this support as otherwise he would not remember to change his clothes. Aida described how Jimmy can be disorientated within the home, particularly in the mornings. Jimmy misses driving a lot.

Social support networks: John and his wife visited Jimmy and Aida every day. John said if they did not, Aida got very anxious. John felt that Jimmy's needs were now being met, as long as he or other family members could drive him, but that Aida was not getting the support she needed.

Interventions and services discussed: Jimmy had been to the CST group at memory services and was now attending a maintenance CST group monthly. He was taken by John, who stayed with him for the groups. Jimmy talked in positive terms about the CST group and the people he'd met there. John also talked positively about the support memory services had offered them and the groups. John told me before and after interview that Aida had been struggling with anxiety. John reported Aida had had individual cognitive behaviour therapy with a clinical psychologist at memory services, but this had now finished. John said a carer's group had been offered to Aida, but she would not go.

Pen portraits: Kathryn (and Phillip)

Kathryn (80 years) was retired. She had been diagnosed with Alzheimer's Disease about a month before interview. Her husband Phillip (80 years) was also retired. I interviewed them together.

History of diagnosis: Phillip said their daughter had encouraged them to go the GP and had accompanied them to memory services when the GP had referred Kathryn there.

Co-morbidities: none reported

Acknowledgement of diagnosis and awareness of changes: Phillip explained how he needed to do the cooking now as Kathryn found organising timings difficult and had on occasion, used the wrong items in the oven or on the stove. When Phillip gave examples of how the dementia was impacting on their lives, Kathryn did not acknowledge this, she said she felt busy and was always doing things.

Personal interests and activities: They were attended church regularly and were involved in a welcoming committee. They had spent their retirement holidaying and cruising and liked gardening. They said they do most activities together although Kathryn attends a monthly women's guild meeting alone.

Social support networks: They had a daughter who did not live locally, who visits mostly monthly.

Interventions and services discussed: They had both attended a memory café once and were planning to return. Phillip said they had been given information about possible groups at memory services, but that it was not an easy location for them, and Kathryn could not travel there alone. Phillip said he felt it was early days for them and they did not really need any further support at the moment.

Pen portrait: Angela

Angela (70 years) lived alone. I interviewed her alone. Angela said she was diagnosed with Alzheimer's Disease a 'matter of months ago'. She had retired from work following the diagnosis, but said she had been working up until then.

History of diagnosis: Angela says she went to the GP as her daughter noticed problems with her memory that she herself was unaware of.

Co-morbidities: none reported.

Acknowledgement of diagnosis and awareness of changes: Angela said she did not feel any different and hoped the diagnosis was wrong. However she also talked about having to accept it. Angela became very tearful during part of this interview and explained how she would kill herself if she got the point of not being able to function independently or remember people. For her, 'shuffling around a care home' would be unacceptable and she felt death to be preferable. She said she had always enjoyed intellectual pursuits the life of the mind was vital to her so she did not want to envisage a future where she might not have full capacity. She said she was not going to kill herself now, she was not there yet. Angela said she felt like she had been made to stop work. She talked about being angry and frightened.

Personal interests and activities: Angela had been a mature student and talked about how much she valued learning. She said she enjoyed walking, driving, watching films and reading books. She said the doctor said she should give up work and her work colleagues also assumed she would stop working. She herself had decided she would not take any more clients on. She was devastated by the loss of this work role, something she valued greatly and had worked hard to achieve. She also worried about the loss of income and losing her house.

Social support networks: Angela had a daughter and two grandchildren. She said her daughter visits regularly but she has been seeing less of the grandchildren recently. She also talked about how friends had distanced themselves since she told them she has Alzheimer's.

Interventions and services discussed: Angela had been to a CST group over several weeks and said that whilst she would go to everything that was offered, she also found it frightening and sad seeing others more severely affected, and also that that another group member had been rude to her.

Pen portraits: Iris, Len and Pauline

Iris (74 years), was diagnosed with mixed type dementia (vascular and Alzheimer's Disease), about five months prior to interview. She and her husband Len were retired. They were interviewed together. Their daughter Pauline was also present and consented to interview. Although I had not known she would be there, she was present when I arrived and had read the information sent to her parents.

History of diagnosis: Len had taken took Iris to the GP as he had noticed a deterioration in her memory, and she was referred to memory services.

Co-morbidities: Iris experienced a major stroke in 18 years ago and had used a wheelchair ever since. She had a right sided paresis and blurred vision. Len had been her full time carer since then.

Acknowledgement of diagnosis and awareness of changes: Len said, other than a diagnosis, there was not any difference in their lives compared to before the diagnosis. Iris did not seem aware of the diagnosis or any difference in herself.

Personal interests and activities: Iris was reliant on Len for help with her personal and domestic care. Len said they try to go out most days, he drives them to a garden centre or shopping centre for coffee or cake. Len plays competitive bowls and takes Iris with him when the facilities are accessible. They go to Church regularly.

Social support networks: Iris and Len had moved to their current home from another part of the country about six years ago, to be nearer to their daughter and granddaughter.

Interventions and services discussed: Iris and Len had been attending a CST group at memory services each week, but Iris did not recall this when I asked about it. When prompted with a few words by Len she did appear to recall it. Len said she was happy when she was there and had seen an improvement in her over the weeks she had been attending in terms of her recall of what they were doing there and engagement in the sessions, he also felt the medication she had been put on was helpful.

Len had also seen a carer's service which found valuable, as he had found the staff member empathetic and professional, he had been visited at home and been information about services to use or not use, as they wished. He said he felt he knew where to go for support when he needed it but did not need any further support as yet. Len said he had also attended a six week carers group run by the Alzheimer's Society, which he had valued. He had organised a sitter for Iris as he cannot leave her for more than about an hour. Since then he has been trying to arrange a sitter more regularly so that he can have a break. However he said he and Iris do not want a stranger to come, so he is asking some of the ladies from church. Len said he thought they would try visiting a memory café soon, as it was good for them to get out and meet other people.