

**The Journey from Uncertainty to Certainty and Back Again:
Experiences of Neuropsychological Assessment for Possible Dementia,
using Interpretative Phenomenological Analysis**

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Abstract

Background: Dementia has become a global public health and social care priority (World Health Organisation, 2012b). In England, the National Dementia Strategy promoted a drive towards earlier diagnosis of dementia (Department of Health, 2009). An important part of the transition from one's identity without dementia, to a person with dementia is being assessed for cognitive impairment. Currently, little is known about peoples' experiences of being assessed for possible dementia, or how they make sense of, adapt and cope with this process. Previous research has predominantly focused on exploring experiences of people who are living with dementia, from the point of diagnosis. The current study aims to add to the understanding of the "dementia journey", by exploring participants' experiences of undergoing a neuropsychological assessment for possible dementia.

Method: This study employed a qualitative design. Semi-structured interviews were used to explore participants' experiences of neuropsychological assessment for possible dementia. Eight participants were interviewed, after they had completed their neuropsychological assessment. Assessment outcomes were mixed, and not all received a diagnosis of dementia. Interview transcripts were analysed using Interpretative Phenomenological Analysis.

Results: Four interrelated superordinate themes emerged from the interview data, which represented participants shared experience of neuropsychological assessment. These were: "Things aren't right: what's wrong with me?", "Testing by name, testing by nature", "Professional roles: different sides of the same coin", and "Finding out....". Neuropsychological assessment experience was depicted as a journey characterised by uncertainty and participants' search to make sense of and ameliorate that uncertainty.

Conclusions: Undergoing a neuropsychological assessment for possible dementia can be a distressing and uncertain experience, despite professionals' efforts to explain the assessment process. Current clinical practices should be reviewed and adapted to best meet the needs of people being assessed for possible dementia. Future research that explores experiences of other types of dementia assessment would be interesting.

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1.0 Introduction

1.1 Overview

The Alzheimer's Society (2014a) estimates that there are over 800,000 people with dementia in the United Kingdom (UK). The way in which dementia is conceptualised has a significant impact in shaping how a person living with dementia is viewed at both an individual and societal level, and the type of interventions offered. The previously dominant biomedical model of dementia has been widely criticised for generating a deterministic view of dementia whereby the person who has dementia is viewed as a disease entity rather than an individual who happens to be living with dementia (Beard & Estes, 2002; Harding & Palfrey, 1997; Lyman, 2000). However, it is increasingly recognised that psychosocial factors have a significant influence on the dementia process (Bender & Cheston, 1997; Kitwood, 1997a). This re-appraisal of dementia has prompted new research into exploring the meaning of dementia from the perspective of the person experiencing it. To date research has primarily focused on post-diagnostic experiences (Bunn et al., 2012; Caddell & Clare, 2010; De Boer et al., 2007; Steeman, De Casterlé, Godderis, & Grypdonck, 2006). However, little is known about an individual's experience during other aspects of the dementia pathway, particularly the transition of becoming a person with dementia. Consequently, the present study aimed to understand more about this transitional process, by exploring peoples' experiences of undergoing a neuropsychological assessment for possible dementia.

This chapter will begin by discussing changing world demographics and the implications of this on prevalence of dementia, to establish the study context.

Current conceptualisations of dementia will then be presented and explored. Existing research covering post-diagnostic dementia experience and associated models of coping and identity will be discussed. Current dementia assessment procedures and national clinical guidelines will then be outlined. Existing research exploring dementia assessment experience will be reviewed and evaluated. The rationale for the present study, aims and research questions, will be presented.

1.2 Changing World Demographics: Ageing Populations

Over the past century, the global demographic landscape has sustained considerable change. Worldwide populations have grown and age composition has altered. Advances in medicine and healthcare has meant that less people are dying at a younger age from acute infectious and parasitic diseases, resulting in more people living into old age (World Health Organisation [WHO], 2011).

Data on global demographic trends reported significant increases in life expectancy worldwide. Life expectancy increased from 65 years in 1950 to 78 years old in 2013, in the most developed countries of the world. (United Nations [UN], 2013). Projections indicated that this trend is set to continue (UN, 2013).

At the same time, changes to the UK population profile have mirrored global trends. The proportion of older people (≥ 65) in the UK rose from 15% in 1985 to 17% in 2010, representing an increase of 1.7 million (Office for National Statistics [ONS], 2012). This is expected to increase to 23% by 2035 (ONS, 2012). In the UK in 2012 there were 11 million people aged 65 and over, of which 3 million were aged 80 and older (Cracknell, 2010). Life expectancy has also increased

considerably from 58 years for men and 62 years for women, in 1931 (Help the Aged, 2009), to 79 years for men and 83 years for women, in 2012 (Age UK, 2014).

One important consequence associated with increasingly ageing populations is a rise in the number of people living with dementia. Although not considered a normal part of the ageing process, ageing is a key risk factor associated with the onset of dementia (Yip, Brayne, & Matthews, 2006). Therefore, as population ageing is predicted to continue, more and more people are likely to be directly or indirectly affected by dementia, in the future.

1.3 Dementia: Epidemiology and Etiology

1.3.1 Overview of dementia

Dementia is an umbrella term, which refers to a range of chronic and progressive brain diseases that can have devastating consequences and significantly limit life expectancy. Symptoms of dementia may vary between individuals. However dementias are routinely associated with deterioration across a number of domains; including cognition, which can affect memory function, learning, orientation and language; physical, psychological and social functioning (Alzheimer's Disease International [ADI], 2009). Overtime, a person's functioning progressively declines, affecting their ability to manage many aspects of their life, and ultimately resulting in them becoming dependent on others for care. However, consequences and experience of dementia can vary significantly between individuals.

1.3.2 Prevalence of dementia

Dementia prevalence data estimated that in 2009 35.6 million people aged 60 and over had dementia, worldwide (ADI, 2009). A recent WHO (2012a) report also estimated that 7.7 million people worldwide were being diagnosed with dementia per year (WHO, 2012a). With life expectancy predicted to increase at a rate of approximately 2 years per decade (Oeppen & Vaupel, 2002) the prevalence of dementia is also expected to rise (Alzheimer's Society, 2007). A prevalence-diagnosis gap was also identified which estimated that as many as 28 million people may be currently living with dementia without a diagnosis (Alzheimer's Society, 2014a).

In the UK a recent review of dementia prevalence rates estimated that in 2013 over 815,000 people were living with dementia (Alzheimer's Society, 2014a). Overall UK population prevalence of dementia was estimated at 1.3%, which equates to one person in every 79 people having dementia.

1.3.3 Impact of dementia

The impact of dementia is wide reaching affecting individuals, families and societies. The total cost of dementia in the UK was estimated at £26.3 billion, in 2014 (Alzheimer's Society, 2014a).

Yet the true cost in terms of individual loss and family impact is much more difficult to estimate. As a person's ability to manage independently declines many families take on the responsibility of caring for their loved ones (Morrison, 2008).

Given the increasing number of people who have or are likely to develop dementia, this highlights the urgent need to understand more about the causes and

consequences of dementia, and the necessity to develop effective interventions to tackle the effects of living with dementia.

1.3.4 Risk factors for dementia

There has been much debate about why some people develop dementia and others do not. Epidemiological studies have identified a range of risk factors associated with increased vulnerability to developing dementia (Sosa-Ortiz, Acosta-Castillo, & Prince, 2012), including advancing age, which is considered the greatest risk factor for developing dementia (Alzheimer's Society, 2013a; (Yip et al., 2006), genetics (Green et al., 2002; St. Clair et al., 1995), pre-existing chronic health conditions (e.g., diabetes, hypertension, obesity) (Luchsinger et al., 2005; Whitmer, Sidney, Selby, Johnston, & Yaffe, 2005), and a past history of head injury and stroke (Patterson, Feightner, Garcia, & MacKnight, 2007; Sosa-Ortiz et al., 2012). Conversely, evidence suggests that higher level of education, IQ, occupational attainment (Mortimer, Snowden, & Markesbery, 2003; Sosa-Ortiz et al., 2012; Valenzuela & Sachdev, 2006), and maintaining a physically and mentally active lifestyle (Hamer & Chida, 2009; Wang, Karp, Winblad, & Fratiglioni, 2002), may well have a strong protective effect against the onset of dementia.

1.4 Conceptualising Dementia

The way in which dementia is conceptualised, is important for a number of reasons: it informs the type of interventions that are developed to treat and/or support a person who has dementia, and it also shapes wider societal perceptions about what it means to be a person living with dementia.

1.4.1 Medical model of dementia

Historically, the medical model has dominated the conceptualisation of dementia. Broadly speaking, the medical model, sometimes also referred to as the “illness” model, aims to differentiate people who are well, from those who are not, by identifying symptoms and making a diagnosis, which informs type of treatment used (Cheston & Bender, 1999). From a medical perspective dementias are understood by clinical symptomology depicting progressive cognitive and physical decline, underpinned by neuropathological changes. Official illness and disease classification systems have been developed to support disorder specific diagnoses. According to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) (American Psychiatric Association [APA] 2013) “dementia”, labeled as “major neurocognitive disorder”, can be defined as cognitive decline, from previous level of functioning, in at least one domain (e.g., attention, executive functioning, learning and memory, language, perceptual-motor and social cognition) (Agronin, 2014; APA, 2013).

1.4.1.1 Subtypes of dementia. To support a medical understanding of dementia disease profiles, different subtypes of dementia have been identified and categorised according to the nature and pattern of neurological deterioration and corresponding cognitive and functional impairment. There are many different subtypes of dementia with the most common being AD, VaD, Dementia with Lewy Bodies (DLB) and FTD (Alzheimer’s Society, 2013a; Robillard, 2007).

Although medical classifications of dementia attempt to identify and dissociate subtypes of dementia based on clinical symptomology and patterns of

neuropathological degeneration, this is not always easily achieved. In clinical practice people may exhibit symptoms and neuropathology that do not discretely match one particular subtype of dementia, resulting in some people being diagnosed with having a “mixed dementia”, which is estimated to account for up to fifth of dementia diagnoses in the UK (Alzheimer’s Society, 2014a).

1.4.1.2 Stages of dementia. Although it has been recognised that symptoms of dementia can vary between individuals, within the medical model, various attempts, have been made to classify the progression of dementia, in terms of early-, middle- and late-stages (ADI, 2009; WHO, 2012a). These “stages” also loosely correspondence with the DSM-5 specifiers for dementia severity (mild, moderate, and severe) associated with degree of cognitive, functional, psychological and social impairment, and to some degree have been used to inform type of medical intervention and level of support provided (APA, 2013).

1.4.1.3 Critique of medical model of dementia. Whilst it is important to acknowledge the clinical contribution the medical approach has made (e.g., increasing awareness of dementia as a disease, developing subtype classifications to aid diagnosis, establishing genetic risk factors, identifying certain cellular precipitants, and promoting medical research aimed at developing pharmacological treatments), it has been widely criticised for generating an incomplete picture of the dementia process (Beard & Estes, 2002; Harding & Palfrey, 1997; Lyman, 2000).

Viewing dementia as primarily a disease entity has huge implications in terms of how a person with dementia is viewed and treated by others, as well as affecting how they feel about themselves. Adherence to this narrow disease oriented

focus has been criticised for generating a negative discourse, where the person with dementia is depersonalised and considered “an object” of this disease and a source of burden, rather than “a responsive person” who is trying to adapt to living with dementia (Beard, Knauss, & Moyer, 2009; Cottrell & Schulz, 1993, Lyman, 2000). This perspective has also been implicated in the stigmatisation of dementia and may explain why treatments for dementia have historically primarily focused on physical care, meeting basic needs and controlling “problem-behaviours” with medication (Kitwood & Benson, 1995; Robertson, 1990).

Furthermore, in seeking to understand dementia purely from the perspective of brain functioning and cognitive decline, this approach neglects to consider the role personal factors, and social context might have on an individual’s experience of living dementia (Cheston & Bender, 1999).

Research has also demonstrated that many people with dementia, experience “excess disability”, whereby degree of functional impairment is greater than that which can be explained by neurological deficits alone (Brody, Kleban, Lawton, & Silverman, 1971; Sabat, 1994). Moreover, variability of symptom severity has been observed in individuals with similar pathology (Downs, Clare, & Anderson, 2008).

Arguably, taken together, this evidence suggests that the medical model alone provides an insufficient explanation of the dementia process, and that the contribution of other factors needs to be considered.

1.4.2 Psychosocial perspectives of dementia

Dissatisfaction with conceptualising dementia purely from a biomedical perspective, prompted researchers to consider how other factors might influence the dementia process. This led to the development of number of psychosocial perspectives of dementia, which will be described and discussed below.

1.4.2.1 Towards a biopsychosocial model of dementia. Kitwood (1990) proposed a comprehensive “dialectical model of dementia” to describe how the development and course of dementia can reflect the interaction of social, psychological and biological factors. Factors seen as influencing a person’s experience of dementia included their personality traits, previous life experiences, physical health, and social context, in addition to neurological decline. Kitwood (1993) conceptualised dementia in the form of a simple equation:

$$D = P + B + H + NI + SP$$
 (where D = dementia, P = personality, B = biography, H = physical health, NI = neurological impairment, and SP = social psychology).

Kitwood (1993) was also amongst the first to advocate a person-centred approach to understanding dementia. Much of his work emerged from observing residential care environments, and speaking with people who were living with dementia, and their carers/family. From this work he specifically emphasised the impact social environment can have in shaping a persons experience of dementia, in respect of how the person sees themselves, and also how they are viewed and treated by others (Kitwood, 1993; Kitwood & Bredin, 1992). Kitwood (1993) coined the term “malignant social psychology” to describe how negative social interactions can

have a detrimental impact on the person with dementia, resulting in them being depersonalised, invalidated and ultimately overlooked, “leading to greater disability and dysfunction” (Woods, 2001, p. S7).

1.4.2.2 Subjective experiences of dementia (Bender & Cheston, 1997).

With Kitwood (1993, 1997a, 1997b) bringing the person with dementia into focus, other researchers began to consider how the dementia process might impact on the person with dementia. Bender and Cheston (1997) proposed a tripartite model of subjective experiences of dementia. This model highlights how having dementia can elicit a range of emotional, behavioural and social responses, which in turn can influence a person’s dementia experience, and thus clinical presentation of dementia.

1.4.2.2.1 Emotional reactions. Bender and Cheston (1997) described how people may experience a range of different emotional reactions in response to living with dementia. They distinguished between four different types of feeling: anxiety, depression, grief and despair.

Bender and Cheston (1997) suggested, how for instance, feelings of anxiety and despair might be triggered by uncertainty and confusion about what is happening to them, which may then be further compounded by the threat of inevitable, yet unpredictable, future decline. Depression and grief were depicted as a reaction to multiple losses: the loss of current skills and abilities, social roles, and changes in relationships; as well as grieving for anticipated future losses. Rather than representing a sequential process of emotional adaptation, Bender and Cheston (1997) suggested that feelings elicited by dementia could be extreme and varied, and influenced by an individual’s appraisal of dementia.

1.4.2.2.2 Behavioural responses. Bender and Cheston (1997) also highlighted how people might respond in different ways, as they attempt to manage their emotional reactions and adjust to the effects of progressive cognitive loss. They argued that it is possible to differentiate between “primary” symptoms of dementia, underpinned by neurological change (for example, memory loss, language impairment); and “secondary” symptoms, reflecting underlying psychological processes of adjustment and coping. For example, lack of awareness might reflect an underlying self-protective denial response, and apathy and withdrawal might be indicative of symptoms of depression, rather than occurring as a result of neurological change.

1.4.2.2.3 Social context. In addition to personal factors, social context was also cited as a key influence in shaping a person’s dementia experience. Bender and Cheston (1997) described a reciprocal relationship between emotional behaviour and social environment, whereby social context may act to regulate emotional expression, and type of emotional behaviour may influence social responses.

Overall, these models acknowledge the contribution personal psychology and social context can have in influencing the dementia process, and represent a change in the way dementia is conceptualised, from being disease-focused to person-centred, thus bringing the person with dementia into focus. This also highlights that whilst certain aspects of dementia are beyond control of the individual and their environment, others may be amenable to change

1.4.2.3 Process of dementia: stages of psychological adaptation. As outlined above, the medical model categorises the dementia process in terms of

stages of severity, and associated progressive cognitive, functional and social loss (see section 1.4.1.2). However, other theorists have proposed that the process of dementia might also be viewed from the perspective of representing stages of personal psychological adaptation, in which the person living with dementia actively seeks to make sense of and cope with the consequences of having dementia (Cohen, Kennedy, & Eisendorfer, 1984; Keady & Nolan, 1995a, 1995b).

Informed by Kubler-Ross' work on psychological response to dying/loss, Cohen et al. (1984) conducted a qualitative study, aimed at exploring psychological change in relation to dementia progression. Based on interviews with several hundred people with AD, Cohen et al. identified six phases of psychological reaction: recognition and concern (pre-diagnosis); denial (during diagnosis); anger/guilt/sadness, coping, maturation, and separation from self (post-diagnosis). Phases of change were associated with different aspects of the diagnostic pathway, rather than aligned with illness severity per se. Cohen et al. suggested that people perceive and react to losses throughout the course of the illness, beginning long before they receive a diagnosis, occurring during diagnosis, and beyond.

In another study, Keady and Nolan (1994) presented a tentative longitudinal model of the dementia process, from the person with dementia's perspective. They outlined nine stages, beginning in the pre-diagnostic phase through to death. Stages were described as: slipping, suspecting, covering up, and revealing (pre-diagnosis); confirming (seeking diagnosis); surviving, disorganisation, decline and death (post-diagnosis). This model was developed from clinical observations and through interviews with family members of people with dementia, therefore may not

represent the actual experiences of people with dementia. The authors highlighted the importance of validating their proposals by including the perspectives of people with dementia in research (Keady & Nolan, 1994). Subsequently, in a further study, 10 people with early stage dementia were interviewed about their experiences of the dementia process (Keady & Nolan, 1995a; Keady & Nolan, 1995b). Keady and Nolan found support for the first five stages of the model (slipping to confirming), where similar experiences were reported to those expressed by family members. However, some aspects of the model were further revised, for example some participants interviewed described more positive aspects of post-diagnostic experience (labeled as “surviving”), providing examples of how efforts were made to optimise functioning (relabeled as “surviving/maximizing”), demonstrating active adjustment rather than passive resignation (Woods, 2001).

These perspectives were seen as supporting a changing view that rather than being a passive victim of neurological decline, the person with dementia can be seen as actively trying to make sense of, adjust and cope with the consequences of living with dementia.

1.5 Understanding Lived Experience of Dementia.

The re-appraisal of dementia as a biopsychosocial process has prompted new research into exploring the meaning of dementia from the perspective of the person experiencing it. To date research has primarily focused on lived experiences, from the point of diagnosis and beyond, attempting to understand the psychological and social impact, and consequences of living with dementia, to develop empirical

knowledge and inform person-centred care (for review see Bunn et al., 2012; Caddell & Clare, 2010; De Boer et al., 2007; Steeman et al., 2006).

A selection of studies that explored lived experience of dementia will be presented and discussed in the sections that follow. The aim being to highlight and summarise key issues that emerged from this research, and which provide a contextual background to the present study.

1.5.1 Dementia diagnosis experience

A number of studies have explored experiences of dementia diagnosis, taking into account views from both the person with dementia and their family/caregiver.

In an early paper, Husband (1999) used a case study approach to describe the psychological impact of a receiving a diagnosis of dementia for three people.

Emotional responses to learning of a diagnosis of dementia were mixed. Two of the three people interviewed reported feelings of shock, anxiety, horror and anger, whereas the third participant reported a reduction in anxiety and relief associated with the confirmation of her suspicions. A common experience to all was the concern with how others might react to the knowledge that they had dementia (for example, thinking they were “mad”, and being avoided/treated differently).

In another study, Pratt & Wilkinson (2001, 2003) interviewed 24 people aged 44-78 years old about their experience of receiving a diagnosis of dementia, and explored their views about any benefits and/or drawbacks of an early diagnosis. Participants described diagnosis disclosure as an intensely emotional time, with many people experiencing a lengthy and complex assessment process in the lead up to diagnosis. Receiving a diagnosis was associated with a range of emotional

reactions, including shock, anger, fear and depression. At the same time, many people felt that their diagnosis validated their experience of cognitive difficulties. Benefits associated with receiving a diagnosis were seen as outweighing drawbacks, and included, making sense of the changes they had noticed in themselves, having the opportunity to make practical plans for the future, and focusing their attention on making the most of their life. Drawbacks seemed more aligned with the impact of dementia as a disease, rather than of receiving a diagnosis per se, and included concerns about loss of self-confidence and becoming less able to complete activities of daily living independently.

Social factors were also seen as important in influencing the experiences people had. Social support from family, friends and services was seen as a key factor in generating positive social contexts. Participants also highlighted the importance of open communication from clinicians, emphasising the importance of choice about whether a diagnosis is disclosed or not, as well as the need for early diagnosis. Withholding a diagnosis from those who wanted to know was experienced as a source of increased distress, and a barrier to maximising adjustment and coping. For some people, views of negative social stereotypes attributed to dementia, resulted in them feeling apprehensive about disclosing their diagnosis.

Robinson, Clare and Evans (2005), aimed to explore psychological reactions to a diagnosis of dementia in couples, where one person had been diagnosed with dementia. Overall, 9 couples were interviewed together about their diagnostic experience. Analysis of the interview data revealed that couples experienced both positive and negative effects as a result of diagnostic disclosure. For some couples,

diagnosis provided relief, helping them to make sense of and accept the difficulties one partner had been experiencing. Others reported that insufficient information was given to them about the diagnosis, prognosis of dementia and sources of support, thus maintaining their uncertainty about their difficulties, and increasing feelings of isolation. The process of acknowledging loss was also a key theme for couples. The authors likened couples experiences of loss to the dual-process model of grief (Stroebe, Schut, & Stroebe, 1998). Robinson et al. (2005) described how couples appeared to oscillate between loss-oriented responses and restoration-oriented responses. Loss-oriented responses involved acknowledging a range of losses, such as memory loss, loss of independence, previous roles, changes in relationships and lifestyle), as well as experiencing feelings of frustration, anger and depression, which accompanied their losses. Restoration-oriented responses referred to ways in which couples attempted to adjust and cope with being told one partner had dementia. Couples described using a range of different coping strategies. Couples who understood and accepted the diagnosis of dementia appeared to find it easier to make adjustments in their life, such as focusing on capability rather difficulties, making adjustments within relationships to compensate for difficulties, and maintaining social contact. Some partners found it difficult to adjust to the loss of their previous relationship and assuming the role of caregiver. Others described withdrawing from social activities and choosing not to disclose their diagnosis of dementia. Withdrawal and secrecy appeared influenced by feeling less confident in social settings, as well as fearing feeling stigmatised as a result of negative stereotypes associated with being a person with dementia.

In a later study, Aminzadeh, Byszewski, Molnar, and Esner (2007), used a similar approach to explore the emotional impact of diagnosis disclosure over time, on people recently diagnosed with dementia alongside their supporter/caregivers ($n=12$, patient/caregiver dyads). Data was collected from a range of sources, involving an audio recording of the diagnosis disclosure session, in-depth patient/caregiver dyad interviews within one week of diagnosis, and a follow-up focus group within a month of diagnosis. The authors identified three key themes, which emerged from the collected data, illustrating powerful emotional responses to diagnosis disclosure, experience of loss and stigma, and feelings of uncertainty and insecurity.

Emotional reactions were described in terms of a process of psychological adaptation over time. For the majority of people with dementia, diagnosis disclosure was accompanied by immediate feelings of shock and distress, with a small minority expressing a sense of relief and confirmation. In the time period after diagnosis, a range of emotional reactions and coping responses were reported, ranging from denial to crisis, as well as actively trying to adapt and maximise existing capabilities.

People with dementia and their caregivers also described experiencing feelings of loss and sadness. For many, being diagnosed with dementia seemed to not only confirm actual losses (i.e., changes in cognitive and functional ability) but also to draw attention to anticipated future losses across various aspects of their life (e.g., sense of control, social roles, relationships, sense of identity). Fears about anticipated losses appeared influenced by perceived negative stereotypes about

living with dementia, informed by own past experiences of family members with advanced dementia, and fears about feeling stigmatised by others.

Uncertainties associated with diagnostic disclosure were reported by many participants (people with dementia and their supporter/caregiver). For some, uncertainty about dementia prognosis appeared to make the prospect of future planning difficult to comprehend. Whilst for others, uncertainty seemed to translate into feeling increasingly insecure, vulnerable and dependent on others.

Other researchers focused specifically on exploring the social impact of a dementia diagnosis. Langdon, Eagle and Warner (2007) interviewed 12 people about the social effects of being diagnosed with dementia. Analysis of interview data revealed 5 key themes associated with social aspects of dementia diagnosis experience: impact of using “dementia” to describe their condition, changing social interactions, question of disclosure to others, loss of social status and role, and uncertainty surrounding diagnosis.

Many participants reported negative connotations associated with the use of the word “dementia” to conceptualise their difficulties and experiences. Dislike of the word “dementia” appeared related to its similarity to “demented” and association with mental illness. Conversely, a small minority thought that having a diagnosis might enable others to understand the difficulties they experienced.

Participants spoke of being extremely conscious of how people reacted to them once they were diagnosed with dementia, feeling that many were perhaps hiding their true thoughts in an effort to protect them. Participants were keen for people to be open and honest, and act as normally as possible.

A key issue that emerged for participants was whether or not to disclose their diagnosis to others. Whilst participants generally felt comfortable disclosing their diagnosis to family, close friends and certain health professionals, they appeared more cautious in sharing this information with people in their wider social circle (e.g., distant family, friends, acquaintances and strangers). Fearing that people may respond differently to them after they have been diagnosed with dementia, and feeling cautious about diagnosis disclosure, was considered influenced by the negative stereotypes surrounding dementia.

Participants also described how they felt their social status had changed as a consequence of being diagnosed with dementia, with many doubting whether they were still of use to society. Being diagnosed with dementia was also associated with increased uncertainty and confusion, and many participants spoke of feeling unsure about the meaning of dementia, and how this differs from “normal” age-related cognitive changes. Confusion appeared further compounded by what participants saw as vague and inconsistent information provided by health professionals at diagnosis. Some participants described how they attempted to make sense of and normalise their difficulties, by comparing themselves to others.

Overall, this research revealed a number of key themes in relation to dementia diagnosis experience. The diagnostic process was experienced as an intensely emotional time, affecting people in a variety of different ways. Feelings of shock, sadness, loss, anxiety, uncertainty and anger were common, whilst others felt a sense relief as their experiences of difficulties were confirmed (Aggarwal et al.,

2003; Aminzadeh et al., 2007; Gillies, 2000; Holst & Hallberg, 2003; Husband, 1999; MacQuarrie, 2005; Pratt & Wilkinson, 2001, 2003; Robinson et al., 2005).

The right to make choices about diagnostic disclosure was clear, with the majority of participants wanting to be diagnosed as early as possible (Connell, Boise, Stuckey, Holmes, & Hudson, 2004; Pratt & Wilkinson, 2001, 2003; Smith & Beattie, 2001; Smith et al., 1998).

Diagnostic disclosure was associated with benefits (e.g., understanding difficulties, planning ahead, and making the most of life) as well as drawbacks (e.g., uncertainty about the future, and fears of becoming useless or a burden to others) (Aminzadeh et al., 2007; Clare, 2003; Cotrell & Hooker, 2005; Harris & Sterin, 1999; Pratt & Wilkinson, 2001, 2003;).

Social factors such as clinical practice, family/carer attitude and support, and provision of information about dementia, were seen as important in shaping the experiences people had, and the way they adjusted to their diagnosis (Harris & Sterin, 1999; Langdon et al., 2007; Pratt & Wilkinson, 2001, 2003; Robinson et al., 2005).

Negative stereotypes about dementia were raised as a key issue, resulting in many people feeling reluctant to disclose their diagnosis to others outside of their immediate family/social circle. Fear of feeling stigmatised negatively impacted on self-confidence, leading some people to withdraw from social activities (Aminzadeh et al., 2007; Husband, 1999; Langdon et al., 2007; Pratt & Wilkinson, 2001, 2003; Robinson et al., 2005).

1.5.2 Post-diagnostic experience: Living with dementia

In the main, much of the research on dementia experience has focused on exploring how people cope with dementia, and the impact this has had on their identity and sense of self.

1.5.2.1 Coping with dementia. A number of models have been proposed to understand the process of coping. According to Lazarus and Folkman (1984) coping represents a person's efforts to manage and adjust to an event perceived as stressful (i.e., in this context, living with the effects of dementia). How well a person adapts and copes is seen as largely influenced by the type of strategy used. This model proposes that coping responses are informed by the individual's appraisal of the stressor and their ability to cope. Coping responses are categorised according to those that are problem-focused, where the person attempts to directly change the situation, and those that are emotion-focused, which is aimed at reducing, preventing or tolerating emotional distress. Successful coping is seen as resolving the stressor, thus restoring balance, whilst ineffective coping is associated with likely increased distress.

Park and Folkman (1997), further developed Lazarus and Folkman's (1984) model by specifying the role of different levels of meaning have in influencing the appraisal process. The model distinguishes two levels of meaning: "global meaning", which refers to a person's beliefs and goals, and "situational meaning", which refers to the meaning which is formed from the interaction of a person's global meaning and circumstances of a particular event (Park & Folkman, 1997).

Park and Folkman (1997) hypothesise that global and situational meaning affect the way in which a person appraises and copes with a stressful event.

Other theorists have sought to explain adjustment and coping within the context of ageing (Atchley, 1989). The central premise of Atchley's continuity theory is that people attempt to cope with stressful situations by applying tried and tested strategies developed over a lifetime of experience.

A number of studies have explored lived experiences of coping with dementia. Gillies (2000, 2001) described a range of strategies people with dementia used to manage the effects of memory decline. Ways of coping were defined as either practical (i.e., note taking, using diaries, notices and/or relying on others' as a provider of "proxy memory"), or emotional, such as disguising difficulties, denial, resignation or acceptance. Many people interviewed also emphasised the importance to them of maintaining a sense of control over their life.

Other studies sought to understand coping within the broader context of overall dementia experiences (Clare, 2002; Lee, Roen, & Thornton, 2014; Menne, Kinney, & Morhardt, 2002; Ostwald, Duggleby, & Hepburn, 2002; Pearce, Clare, & Pistrang, 2002; Phinney, 1998; Preston, Marshall, & Bucks, 2007).

Similarly, all studies noted a number of ways in which people with dementia attempt to adjust and cope with the effects of dementia. Studies differed in the way coping was understood.

Ostwald et al. (2002) explored experiences of coping with dementia within the context of managing losses. The authors suggested that dementia was predominantly experienced as multitude and succession of losses, sustained across a

number of areas of life (e.g., loss of memory, loss of relationships, loss of control, loss environment, loss of an anticipated future). Coping was seen as a way of managing and adjusting to such losses. A number of coping strategies were identified, including disclosure, denial, acceptance (cognitive strategies); relying on family support, being helpful to others, isolating self from others (social management strategies); maintaining independence and choosing activities within capabilities (behavioural management strategies), although reasons for choosing certain strategies and success of these was not considered.

Other studies have suggested that coping with the effects of dementia is underpinned by a desire to want to maintain continuity in life, and that this desire influences the type of coping strategies used (Menne et al., 2002; Phinney, 1998). Menne et al. (2002) noted that in coping with effects of dementia, people demonstrated continuity in a number of different ways, such as responding to situations in the way they always had, or adapting the way they coped to maintain continuity of lifestyle, inline with Atchley's (1989) theory of adjustment. For example, denial might act to preserve a sense of self as a person who does not have dementia, using memory aids may sustain a view of self as independent and capable.

Clare (2002) elaborated on the process of coping with dementia, further, by exploring the interaction between people's appraisals of AD, and coping strategies adopted. Clare (2002) suggested that coping strategies adopted by people with AD were influenced by a number of factors, including an individual's emotional responses and the reasons they attributed to the changes they experienced. Coping was viewed as an ongoing process, with strategies used seen as falling on a

continuum, from being self-protective (aimed at maintaining a sense of self) to integrative (where sense of self was adjusted to include changes experienced). People with AD attempted to use a range of different coping strategies to manage the effects of AD, including those that were problem-solving focused (e.g., using external aids, relying on a partner, becoming more informed about AD) and those that were emotion-focused (e.g., hoping for a cure, engaging with reality, acceptance), consistent with theories of coping (Lazarus & Folkman, 1984).

Other studies also identified similar patterns of coping in people living with AD (Lee et al., 2014; Pearce et al., 2002; Preston et al., 2007), although other factors also emerged as important in influencing coping practices adopted. For example, in a study exploring how men cope with AD (Pearce et al., 2002), key issues arose about managing the impact of AD on gender roles and identity. Men described how they felt AD had compromised their sense of manhood, which seemed further reinforced by changes experienced in their marital roles (e.g., becoming more reliant on their wife for support). Adapting practices to manage changes in gender identity (e.g., doing less tasks identified as “male”, feeling more dependent on their wife, less the “head of the family”) were experienced as much more painful than those which tackled more practical issues (e.g., using diaries and lists to compensate for memory difficulties). Pearce et al. (2002) concluded that the meaning people attribute to changes associated with the effects of AD, has a significant impact on emotional reactions, type of coping strategies adopted and emotional experience of adjusting; inline with theories of coping and meaning making (Park & Folkman, 1997).

Preston et al. (2007) suggested that the main “task” of coping with dementia, is to manage a changing sense of identity brought on by the effects of dementia. Managing identity was described as an ongoing process in which people with dementia were trying to make sense of the meaning and effects of dementia, and identify ways of adjusting to this. Similarly to Clare (2002), coping strategies were seen as either aimed maintaining a prior sense of self, or adjusting to accommodate new aspects of identity experienced as a consequence of having dementia. The impact of social context on coping also emerged as important. Feeling cared for and understood, enabled people with dementia to talk more openly about their experiences with family and friends. Being amongst people with similar experiences helped to normalise experiences; for some this increased sense of understanding and acceptance acted to reduce distress, whilst for others this appeared to compound fears about the “realness” of their own situation (Pearce et al. 2007).

Attitude of others also affected how people with dementia felt about themselves and how they coped (Beard 2004; Gillies, 2000, 2001; Harman & Clare, 2006; Lee et al., 2014; Ostwald et al. 2002; Pearce et al., 2002). Many people with dementia described feeling stigmatised by what they consider is a negative social stereotype about people with dementia (e.g., “lost their mind”, “incapable”, “burden on others”; in common with findings discussed in relation to experience of dementia diagnosis (see section 1.5.1). Withdrawing from “risky” social activities and/or hiding their difficulties (where possible) were seen by some as a way of minimising their exposure to being stigmatised and judged (Beard, 2004; Caddell & Clare, 2011;

Harman & Clare, 2006; Ostwald et al., 2002; Pearce et al., 2002; Preston et al., 2007).

Overall, these studies have been helpful in demonstrating how people attempt to adjust and cope with the effects of dementia in a variety of different ways ranging from those that are aimed at maintaining a prior sense of self to those that work to integrate changed experiences into a new sense of self.

A range of adaptive coping strategies were identified included emotion-focused strategies, such as accepting changes and help from others, and problem-focused strategies such as using memory aids and focusing on what can be achieved (Aggarwal et al., 2003; Clare, 2002; Gillies, 2000, 2001; MacQuarrie, 2005; Ostwald et al., 2002). However for some, the experience of living with dementia resulted in passive and maladaptive coping such as denial and withdrawal from everyday life (Bender & Cheston, 1997; Clare, 2003; Gillies, 2000, 2001; Ostwald et al., 2002).

Coping strategies adopted were seen as influenced by individual's appraisal of the meaning to them of the effects of dementia, and their perceived ability to cope (Clare, 2002; Pearce et al., 2002).

Social context influenced ways in which people coped with dementia: feeling cared for and understood enabled people with dementia to openly discuss their experiences with others (Clare, 2002; Ostwald et al., 2002; Preston et al., 2007). Conversely, feeling stigmatised by others' negative perceptions of dementia led many people with dementia to actively try and conceal their difficulties and

withdraw from social activities (Beard 2004; Gillies, 2000, 2001; Harman & Clare, 2006; Lee et al., 2014; Ostwald et al. 2002; Pearce et al., 2002).

1.5.2.2 Impact of dementia on identity and sense of self. Other studies have focused more specifically on exploring the impact of dementia on sense of self and identity (Caddell & Clare, 2011; Harman & Clare, 2006; Sabat & Harré, 1992; Sabat, 2002).

Several studies examined the impact of dementia on selfhood from a social constructionist perspective (Sabat, 2002; Sabat & Harré, 1992). According to Sabat and Harré's (1992) social constructionist model, selfhood comprises of three forms: the self of personal identity (Self 1), expressed through use of personal pronouns; personal traits and attributes and beliefs about attributes (Self 2); and various social identities (Self 3), which requires the involvement of others. In relation to dementia, research suggests that whilst personal identities remain intact, social identities and maintenance of personal attributes, can be lost as a result of the way in which others view and treat the person with dementia (Sabat, 2002; Sabat & Harré, 1992).

Caddell & Clare (2011) explored how people with mild dementia perceive the effects of dementia on their sense of self. Overall, sense of self was seen as relatively unaffected by dementia. People described many aspects of themselves, which they felt had remained the same since the onset of dementia (e.g., personality traits, attitudes, religious beliefs). Differences that were experienced, related more to specific issues such as symptoms and changes in emotional reactions to having dementia, rather than affecting their identity as a whole. There was increased uncertainty about the future effects of dementia on their sense of self, with many

people reporting that they preferred “not to look ahead”. Caddell and Clare (2011) hypothesised whether focusing on continuity rather than change, may be a way for people with dementia to preserve their current sense of self.

Gaining an insight into how individual’s cope with dementia and the impact of dementia on sense of self has allowed interventions to be tailored to address their specific needs, with the aim of maximising wellbeing and quality of life. Indeed NICE (2006) guidelines suggest a number of evidence-based interventions for supporting people with dementia and their carers (e.g., cognitive behaviour therapy, cognitive stimulation therapy, post-diagnostic counselling, reminiscence, occupational therapy).

Overall, this person-centred research has begun to construct a more comprehensive picture of what it means to live with dementia, extending the narrative beyond the parameters of loss and helplessness.

1.5.3 Pre-diagnostic experience

As a dementia journey often begins before diagnosis, people become aware of changes to their memory functioning and other important aspects of their daily life (Cohen et al., 1984; Keady & Nolan, 1994, 1995a, 1995b). Little is known about this process, which remains largely under researched. An important part of a transition from one’s identity without dementia, to a person with dementia, is being assessed for cognitive impairment. It is currently inadequately understood the role the assessment process plays in this transition, or how people make sense of, adapt and cope with being assessed. By understanding more about the impact of this process, it is possible that interventions aimed at optimising wellbeing and

successful adjustment to dementia may be initiated earlier. Furthermore, gaining an insight into experiences of the assessment process may be helpful to adapt current clinical assessment practices to be more in line with client needs.

1.5.4 Dementia assessment

Current dementia assessment practices involve administering a range of cognitive and medical assessment procedures. The purpose being to differentiate any observed cognitive decline from normal age-related changes, and to exclude other explanations for deficits (i.e., physical health, medication, psychological factors). With the absence of definitive biomarkers for all forms of dementia, the diagnostic process can be complex and prolonged (Downs, Clare, & Anderson, 2008; Robillard, 2007; Visser, Vos, van Rossum, & Scheltens, 2012).

The National Institute for Health and Clinical Excellence [NICE] (2006) have developed guidelines for dementia assessment. These guidelines recommend adopting a comprehensive approach to assessment, involving: obtaining a detailed history, cognitive and mental health assessment, physical health screening and reviewing medication (to rule out alternative explanations for reported changes in cognitive functioning). The majority of formal dementia assessments are conducted in secondary care services via specialist memory clinics, with a number of diagnoses taking place in primary care (Bush, 2007).

Cognitive assessment forms an essential part of the dementia assessment process (NICE, 2006), and can involve the use of brief screening tests or more lengthy and complex neuropsychological assessment (Collerton & Domone, 2014). Cognitive assessment typically involves testing functioning across a number of

cognitive domains, including attention, orientation, immediate and delayed memory, perception, language and executive functioning (NICE, 2006). In some circumstances results from brief screening assessments (e.g., the Montreal Cognitive Assessment (Davis et al., 2015), or the Addenrooke's Cognitive Assessment III (Hsieh, Schubert, Hoon, Mioshi, & Hodges, 2013), in conjunction with other medical tests (e.g. blood screening and neuroimaging) may be sufficient to either exclude or establish a probable dementia diagnosis (Bush, 2007).

However, brief tests may have limited ability to differentiate between different subtypes of dementia, or to accurately represent degree of cognitive decline for people with significantly lower or higher pre-morbid IQ, than average (Collerton & Domone, 2014). Furthermore, evidence suggests that accurate identification and classification in the early stages of dementia can be more problematic (Cullen, O'Neill, Evans, Coen, & Lawler, 2007). This means that some people, for whom brief cognitive is inconclusive, will also require a more comprehensive and lengthy neuropsychological assessment (Bush, 2007; Cox, 2011; Morris, Worsley, & Matthews, 2000). In-depth neuropsychological assessments, typically require several sessions of testing, each lasting 1-1.5 hours, and “integrate quantitative and qualitative cognitive information, with history, background, and knowledge of physical and mental health” (Collerton & Domone, 2014, p.33). Results from such neuropsychological assessment may indicate or exclude a probable diagnosis of a dementia, or return an unclear outcome, warranting further assessment in 6-9 months time, to determine whether cognition is deteriorating.

In summary, the process of dementia assessment can differ between individuals. Some people may be given a diagnosis of a dementia after completing a brief cognitive assessment, whereas for others, their clinical presentation may be less clear, warranting a more complex and lengthy neuropsychological assessment process.

1.5.4.1 Neuropsychological assessment context. The present study aimed to explore personal experience of neuropsychological assessment for possible dementia. As discussed above, assessment practices may well vary between services, therefore the neuropsychological assessment process experienced by participants in the present study is outlined below.

People referred to a psychologist for a neuropsychological assessment had already had an initial service assessment with the memory clinic psychiatrist and completed a brief cognitive screening assessment. Results from this assessment were insufficient to confirm or reject a diagnosis of dementia, hence the referral for a more in-depth neuropsychological assessment. The aim of the neuropsychological assessment was to develop a profile of cognitive functioning to inform possible dementia diagnosis, where appropriate.

Waiting times, from initial assessment to neuropsychological assessment, of several months were not uncommon. The neuropsychological assessment process for this service consisted of four sessions, each lasting 1-1.5 hours duration: an initial clinical interview, two sessions of testing, and one follow-up feedback session (two weeks after the second testing session).

The process of assessment varied across sessions, with some being more naturally person-centred and others more process-focused. Time was taken at the initial clinical interview and feedback session to focus on the individual needs of each person. For example explaining the process, discussing the possible outcomes from assessment, identifying choice about diagnostic disclosure and consent; as well as giving feedback in a client friendly way and providing space to discuss any concerns/worries and offering information about follow up support. People were also given the option of having a person of their choice with them during the clinical interview and feedback sessions. During testing sessions participants were assessed alone. A battery comprising different neuropsychological assessments were administered in a standardised way, using a set of instructions, thus affording little flexibility in the approach used.

1.5.4.2 Early diagnosis. Current Department of Health policy highlights the importance of early dementia diagnosis (Department of Health [DoH], 2009). Benefits associated with early diagnosis of dementia include, better adjustment, earlier commencement of pharmacological and/or psychosocial interventions, opportunity of making future plans (Pratt & Wilkinson, 2003; Robinson, Ekman, & Wahlund, 1998). With more people likely to go through the process of being assessed for a possible dementia, it is important to understand how people experience this process to determine the psychological impact this may have on them and to inform clinical interventions, where appropriate.

1.5.5 Experiences of dementia assessment: a literature review

To date, very few studies have explored the lived experience of individual's as they navigate the dementia assessment pathway. A review of current literature exploring dementia assessment experience will be presented and discussed below.

A literature search was performed using PsychINFO, Cinahl, Embase and Medline databases, on 12th May 2014, 24th February 2015, and 15th December 2015. Search terms used were: dement* OR Alzheim* OR possible dement* OR possible Alzheim*; experienc* OR view* OR perspect* OR understand*; assess* OR neuropsych* OR test* OR cognitive OR psychometric*. All searches were combined and duplicates removed. A manual review of the references of relevant articles was also performed. Results were limited to peer-reviewed articles in English and population age range of 60 years and older. Articles were included if they covered some aspect of the dementia assessment process. Articles that referred solely to experiences related to receiving a diagnosis or post-diagnosis adjustment were excluded. Whilst it is acknowledged that including only peer-reviewed articles, excludes other lived experience material, such as biographies and blogs, this parameter was selected to ensure research quality. Overall, 6 articles were identified that met the search criteria (see Appendix A), 2 studies assessed experiences of dementia assessment within the context of conducting a service evaluation, and 2 papers reported findings based on analysis from the same data set (see Appendix B).

Two studies utilised a service evaluation framework to investigate individual's experiences of being assessed for a possible dementia (Cahill, Gibb,

Bruce, Headon, & Drury, 2008; Willis, Chan, Murray, Matthews, & Banerjee, 2009).

Cahill et al. (2008) used a mixed methods design to explore patients ($n=28$) and caregivers experiences of attending a memory clinic cognitive assessment. Participants were briefly interviewed twice, prior and post assessment. A semi-structured questionnaire was used to obtain both quantitative and qualitative data. Questions were asked about attitudes towards attending the memory clinic (i.e., positive/negative feelings, awareness of problems and worry about problems), reasons behind memory problems, expectations of the service, and experience of assessment and feedback. Interview data were subject to thematic analysis. Results indicated that patients reported more positive than negative feelings about their overall assessment experience. The majority of patients reported that the appointment was beneficial. Assessment outcome explanations were found to be helpful in resolving questions about cognitive difficulties, resulting in many patients feeling positive at the end of the assessment. Despite these results, qualitative data revealed that some patients found the process of being assessed confusing and frightening, seeming to highlight their difficulties, and resulting in them feeling demoralised and embarrassed.

In another study, Willis et al. (2009) used a qualitative approach, incorporating semi-structured interviews, to explore patients ($n=16$) and carers' ($n=15$) experiences of memory clinic services. All aspects of the memory clinic service were explored, with views of cognitive assessment representing a small part of the overall study. Patients and carers were interviewed separately. Open-ended

questions were asked about their experience and evaluation of the service. Interviews lasted between 20 minutes and an hour, and were analysed using Conventional Content Analysis (Hsieh & Shannon, 2005). In respect of dementia assessment experiences, results indicated that many patients found the experience of being cognitively assessed particularly anxiety-provoking with some patients feeling agitated and uncomfortable. Specific worries were identified about incorrectly answering questions, and the consequences of this leading to diagnosis of dementia. Patients also spoke of concerns that this stress would adversely affect their ability to perform tasks. Whilst the majority of patients reported feeling reassured by the staff administering assessments, some experienced staff as patronising and insensitive to their needs.

Overall these studies provide a snapshot of dementia assessment experiences within the context of evaluating memory clinic services. Findings indicate that despite the majority of people assessed reporting positive experiences of the services overall, the cognitive assessment process evoked feelings of anxiety and uncertainty. However, the nature of these studies as service evaluations, did not allow for rich descriptions of participants assessment experiences to be explored, and whilst may be helpful to inform service provision, psychological impact and consequences of assessment was largely unexplored

Other studies have focused more specifically on understanding transitions within the dementia process, including dementia assessment, and exploring subjective experiences within this (Keady & Gilliard, 2002; Koppel & Dallos, 2007; Manthorpe et al., 2013; Samsi et al., 2014).

Keady and Gilliard (2002) used interview data collected as part of a previous research study, which aimed to explore lived experience of AD (Keady & Gilliard, 1999), to map the process of becoming a person with dementia. In the original study (Keady & Gilliard, 1999), 15 people (12 women and 3 men) diagnosed with mild AD, and their supporters, were interviewed together (minimum 6 months, maximum 2 years post-diagnosis) about their experiences of dementia. Grounded theory and constant comparative analysis (Glaser, 1978; Glaser & Strauss, 1967) were used to identify different dimensions of the “dementia journey”. Keady and Gilliard (2002) identified 3 processes within the assessment experience: “acknowledging the challenge” which reflected noticing symptoms and seeking medical advice, “playing the game”, which represented completing the formal assessment, and “considering future options”, which referred to thinking ahead. A major area of concern, which arose from the study, was the sense of insecurity and uncertainty, associated with participants’ assessment experience. Findings also indicated that the assessment process elicited feelings of anxiety, and many people reported finding the assessment process daunting and disempowering. The authors noted a range of reactions during the assessment process, including making excuses, relying on others for clarification and being confrontational which they hypothesised were adopted as a meanings of trying to manage their distress. As a result of these findings, the authors recommended that the model of assessment should be altered to adopt a more person-centred approach.

Importantly, this study was the first to begin to elucidate experiences of dementia assessment. The use of a qualitative methodology and open-ended

questions, has enabled a more in-depth exploration of participants experiences, than the service evaluation designs previously described. However, as the focus of grounded theory is primarily to generate an explanation of a social process, adopting a phenomenological approach may have provided a greater insight into the personal meaning ascribed to those experiences. Indeed, Keady and Gilliard suggested that this study might act a springboard for further exploration of dementia assessment experience. A number of methodological limitations were also observed. Since participants were interviewed at least 6 months post-diagnosis, this delay may have affected accurate and detailed recollection of their assessment. Furthermore, being interviewed alongside their family supporter may have impacted on what participants chose to disclose.

Koppel and Dallos (2007) explored dementia assessment experiences within the context of understanding development of memory difficulties over time. Three participants were interviewed twice (pre- and post- assessment). The study utilised a phenomenological approach, and during their interview, participants were encouraged to discuss their understanding of their memory difficulties, the impact memory difficulties had on their life, and their hopes for their forthcoming cognitive assessment (pre-diagnosis). During the post-diagnostic interview participants were asked about their assessment experiences and whether their understanding of their memory difficulties had changed following the outcome of their assessment. Interview data were analysed using Interpretative Phenomenological Analysis (IPA). An overarching theme of uncertainty emerged from the data. The authors described how participants struggled to make sense of their memory difficulties and viewed

the cognitive assessment as a means of understanding the reason for their difficulties. Assessment experiences were polarised into positive and negative experiences, which appeared influenced by whether participants had received a satisfactory explanation. Issues also arose around professional secrecy and feeling excluded from discussions with family members about their difficulties. Koppel and Dallos (2007) eluded to the role the assessment process and outcome may have in providing meaning to a person's experience of their memory difficulties, although this was not explored in their study. Whilst this study begins to explore aspects of dementia assessment experience, this is conceptualised within the overarching aim of understanding the development of memory difficulties. This means that other aspects of assessment experience involving how people make sense of, adapt, and cope with being assessed, and the impact of assessment on self-identity, remains largely unexplored.

Two further studies (using the same data set) constructed experiences of the assessment and diagnostic pathway for people with cognitive impairment and their carers, to inform a model of care for commissioners of assessment services (Manthorpe et al., 2013; Samsi et al., 2014). Patients with cognitive impairment (AD, VaD or mild cognitive impairment) ($n=27$), and their carers ($n=26$), were recruited from four memory clinics across the United Kingdom. Some participants were interviewed separately and others as dyads. Participants were encouraged to discuss their experiences from initial contact with memory services through to post-diagnostic support. Interview data were analysed using grounded theory involving constant comparative analysis method (Strauss & Corbin, 1998). Manthorpe et al.

(2013) and Samsi et al. (2014) identified four stages along the assessment pathway: initial assessment encounters, assessment processes, diagnostic disclosure and long-term management. Participants reported a positive experience following initial consultations with their GP and saw primary care as a gateway to access specialist memory services. The assessment process was not considered person-centred and was described by many as confusing and lengthy, with prolonged waiting times seeming to compound participants' anxieties. Some participants reported negative experiences of diagnosis disclosure, suggesting that the process of imparting the diagnosis exacerbated feelings of shock. In general, individual practitioners were viewed in a positive light. Support with long-term management was welcomed and practice advice offered viewed as helpful. Recommendations were made for services to adopt a more person-centred approach to assessment, taking into account individualised needs, rather than following generic processes. Pre-diagnosis counselling, involving discussion of expectations and possible outcomes, was also suggested.

1.6 Summary and Rationale

Over the past two decades, research exploring lived experience of dementia from perspective of the person with dementia, has burgeoned. Such person-centred research has had important implications not only in extending knowledge of the dementia process but also in identifying and providing interventions aimed at supporting successful adjustment to diagnosis, optimising functioning and maintaining mental well being, for people living with dementia.

Little is known about an individual's experiences during other aspects of the dementia pathway, particularly the transition of becoming a person with dementia.

Existing literature on experiences of dementia assessment presents some important findings. The assessment process was generally not experienced as person-centred (Keady & Gilliard, 1999; Koppel & Dallos, 2007; Manthorpe et al., 2013; Samsi et al., 2014). Feelings of anxiety, confusion and uncertainty were common (Keady & Gilliard, 1999; Koppel & Dallos, 2007; Manthorpe et al., 2013; Samsi et al., 2014; Willis et al., 2009). The nature of the assessment process was implicated in compounding individual's distress (Keady & Gilliard, 1999; Manthorpe et al., 2013; Samsi et al., 2014). Professional relationships were generally experienced as positive (Cahill et al., 2008; Manthorpe et al., 2013; Samsi et al., 2014; Willis et al., 2009).

There is clearly scope to further explore peoples' lived experience of being assessed for a possible dementia. In particular it would be useful to understand more about the psychological processes that underpin this experience and the consequences of this.

1.7 Study Aims and Research Questions

The particular aim of this study was to utilise a qualitative and phenomenological methodology to explore experiences of neuropsychological assessment for possible dementia, from the perspective of the person being assessed. The present study aimed to explore how people make sense of, react, adapt and cope with undergoing a neuropsychological assessment for possible dementia. It was

hoped that such information would address the gap in current research about dementia assessment experiences, and inform clinical practice in neuropsychological assessment for possible dementia. A qualitative approach was chosen to enable an in depth exploration of participants subjective experiences.

The following research questions have been identified in the context of the study aims:

1.7.1 Primary question

- What are peoples' experiences of undergoing a neuropsychological assessment for a possible dementia?

1.7.2 Secondary questions

- How do people with a possible dementia make sense of the neuropsychological assessment process?
- How do people react to undergoing a neuropsychological assessment for a possible dementia?
- How do people cope with undergoing a neuropsychological assessment for a possible dementia?
- How does undergoing a neuropsychological assessment for a possible dementia impact on self-concept and identity?

2.0 Method

2.1 Design

This study employed a qualitative design. In-depth interviews were analysed using IPA (Smith, Flowers, & Larkin, 2009; Smith & Osborn, 2008), to explore individuals' experiences of undergoing a neuropsychological assessment for possible dementia.

2.1.1 Rationale for qualitative approach

Qualitative research aims to develop an understanding of peoples' experiences as they encounter and live through situations (Elliott, Fischer, & Rennie, 1999). The emphasis is placed on understanding these experiences from the perspective of the person being studied, therefore valuing idiosyncratic differences over generalising to wider populations (Green & Thorogood, 2009). Furthermore, qualitative methods provide a depth of understanding that is not easily achieved through the use of quantitative investigations (Willig, 2008). Qualitative approaches are also considered well suited to under-investigated populations (Elliott et al., 1999). Given that this study aims to develop an in-depth understanding of personal experiences of neuropsychological assessment for possible dementia, in an area of research that is currently inadequately understood, a qualitative approach was considered the most appropriate method to meet the study aims.

2.1.2 Rationale for Interpretative Phenomenological Analysis

IPA was chosen as the preferred methodology for this study for a number of reasons. The primary focus of IPA is to explore, in detail, how people make sense of their personal and social world (Smith & Osborn, 2008). The core principles of IPA

are consistent with the study aims; they are committed to exploring how people try to make sense of their life experiences.

IPA is underpinned by fundamental principles of phenomenology, hermeneutics, and idiography. The importance of these principles in relation to the current study will be discussed in more detail below.

IPA is based on phenomenological ideas and seeks to explore experience in its own terms, focusing on how people perceive the event rather than attempting to describe such phenomena according to a pre-determined categorical system (Smith et al., 2009), more commonly used in quantitative research. It recognises that this ‘personal reality’ cannot be directly accessed and instead involves a process of interpretation.

This process of interpretation is described as a “double hermeneutic cycle”, whereby the researcher attempts to make sense of the participants making sense of their own experiences (Smith et al., 2009). This is aligned with the researcher’s epistemological perspective (see personal statement 2.7.1) of critical realism, in which reality may be viewed as subjective, constructed from life experiences and represented internally. It is also in keeping with the epistemological nature of the study, focusing on personal experiences of being assessed for possible dementia.

IPA is also idiographic. Rather than seeking to make broad generalisations about larger populations it seeks to understand how a particular individual experienced an event or phenomena. This is particularly appealing within the context of the current study as views and opinions of people with dementia have historically been largely ignored. The researcher wanted to utilise a methodology in which the

participants' views were seen as valued and important, and IPA was considered most suited to address these aims.

Furthermore, IPA has been increasingly used in dementia research. By using research methods, which focus on the individual, it has been instrumental in allowing the voice of the person with dementia to be brought into focus. As Kitwood (1997b) emphasised, seeing the person, changes the frame of reference in which dementia is understood, from being the “person-with-DEMENTIA” to the “PERSON-with-dementia” (Kitwood, 1997b, p. 7). This has been beneficial in a number of ways: furthering our understanding of dementia illness experiences post-diagnosis; changing others' perceptions of people with dementia by identifying capabilities rather than focusing purely on impairment; informing changes in service provision; and developing interventions aimed at “enhancing well-being” rather than “containing problem behaviours”. Therefore using IPA was considered the most appropriate method to further develop research into other aspects of dementia experience, which is currently inadequately understood.

2.1.3 Consideration of alternative qualitative approaches

Several different qualitative approaches were also considered in determining the most suitable methodology for this study. IPA was selected over Grounded Theory (GT) as GT focuses on analysing individual accounts at a macro level in order to generate theoretical explanations of sociological phenomenon (Smith et al., 2009). In contrast, IPA offers a more detailed psychological account of subjective experiences, thus enabling individual voices to be heard.

Discourse Analysis was rejected because it focuses on exploring the role of language in constructing social reality, whereas IPA interprets language in order to try and access the meaning of experiences (Smith & Osborn, 2008).

Finally, Thematic Analysis was not deemed appropriate for this study as it offers a more simplistic and descriptive account of broad ‘group’ experiences rather than providing an in depth multi-level analysis that enables the researcher to identify both individual and collective themes (Smith et al., 2009).

2.2 Participants

Participants were people over the age of 60 years old who had completed their first neuropsychological assessment for possible dementia, within the past 6 months.

2.2.1 Eligibility criteria

Eligibility criteria were selected to be as inclusive as practicably possible whilst at the same time following IPA guidelines (Smith et al., 2009). As IPA aims to provide a detailed account of subjective experiences relating to a particular life event, recommendations are to recruit a fairly homogenous sample of participants. Specifically, this study sought to develop a detailed understanding of people’s experiences of being assessed for possible dementia. However, methods of dementia assessment can vary across services, depending on service resources and patients’ needs. Therefore to ensure that a similar type of event was explored, in keeping with IPA requirements, the researcher chose to investigate participants’ experiences of neuropsychological assessment. This type of assessment was chosen as it

encompasses a holistic process, comprising several assessment sessions (clinical interview, completion of range of cognitive assessments and feedback session), and is in line with NICE (2006) recommendations for dementia assessment. Other inclusion criteria and the rationale for these are outlined in the following section.

2.2.1.1 Inclusion criteria. As this study is primarily concerned with understanding the psychological impact and consequences of neuropsychological assessment for a possible dementia within the broader context of aging, only older adults were included, therefore participants were aged ≥ 60 years old. Participants were eligible if they had completed their first neuropsychological assessment for possible dementia, within the past 6 months. Maximum time post-assessment was stipulated to try and ensure that assessment experiences were explored rather than other post-diagnosis experiences. Only participants who were classified as having mild/minimal impairment (a score of 18 or above out of 30 on the Mini-Mental State Examination [MMSE]; Folstein, Folstein, & McHugh, 1975) were eligible to participate. Participants were required to be capable of giving informed consent. Only participants who were able to understand and speak English were eligible. This was considered necessary to allow the participant to fully engage in the interview process and enable the researcher to produce a verbatim transcript of the discussion. Furthermore, using an interpreter would have added a further layer of interpretation to the analysis (i.e., the researcher interpreting the translator's interpretation of the participant's account).

2.2.2 Recruitment

Participants were recruited from a National Health Service (NHS) memory clinic service in East Anglia. A clinician psychologist within the NHS memory clinic identified potential participants who met the research eligibility criteria and sent them a study information pack, on behalf of the researcher. A total of 16 people were identified as eligible to participate in this study. Nine people expressed an interest in the study, of whom 8 participated in the study. The study procedure is outlined in full, in section 2.5 below.

2.2.3 Sample size

Methods used to determine sample size in qualitative research differ from those adopted in quantitative studies. Since the aim of qualitative research is to explore and represent individual experiences, rather than quantify phenomena and generalise to a wider population, formal sample size calculations are not appropriate. Instead, Morse (2000) suggested that a number of factors should be considered when determining sample size in qualitative research. For example, richness of data collected, scope of the study, nature of the topic, the study design and method of analysis proposed. As this study aimed to obtain rich data, within a narrow field of interest, where depth of analysis was prioritised over breadth of experience (i.e. number of cases) and undertaken within a limited timeframe, sample size was intended to be relatively small. Furthermore, Smith et al. (2009) argued that small sample sizes allow the researcher to generate a very detailed account of individual experiences, which is the primary concern of IPA. They suggested a typical sample size range of four to ten participants for professional doctoral research theses

(Hefferon, & Gil-Rodriguez, 2011; Smith et al., 2009) in keeping with IPA requirements to have a small homogenous sample, thus enabling the “same shared event” to be examined in detail

Moreover, a review of studies, that adopted the same methodology to the current study, namely to investigate experiences of living with early-stage dementia, indicated sample sizes ranging from five to twelve participants (Steeman et al., 2006). Therefore this study sample size was also in keeping with other similar research.

2.2.4 Participant demographics

Demographic information for participants recruited is presented in Table 1 below. Participants were 5 men and 3 women aged between 60 and 79 years, who had completed their first neuropsychological assessment for possible dementia, within the past 6 months. Seven participants were of White British ethnic origin, and 1 participant was of Asian African ethnic origin. Participants were interviewed between 1 and 3 months after they completed their neuropsychological assessment. Interview duration was participant driven and varied from 30 to 60 minutes duration.

Table 1

Participant demographics

Participant*	Age	Ethnicity	Outcome	Time since assessment
Terry	67	White British	AD	2 months
David	66	White British	AD	2 months
Jean	79	White British	MCI	2 months
Zeena	65	Asian African	Inconclusive	2 months
Janet	65	White British	Inconclusive	3 months
Derek	64	White British	Psychological factors	1 months
Mick	60	White British	Psychological factors	2 months
Eric	68	White British	No impairment	1 month

Note: AD = Alzheimer's Disease; MCI = Mild Cognitive Impairment
 * = pseudonyms used to preserve participants' anonymity

2.3 Ethical Considerations

2.3.1 Ethical approval

This study was reviewed and granted ethical approval by East of England (Cambridge Central) NHS Research Ethics Committee (Appendix C). Research and development approval was also obtained from Cambridgeshire and Peterborough NHS Foundation Trust, and included permission for recruitment of participants from the specific memory clinic (Appendix D).

2.3.2 Informed consent

All potential participants were given detailed information about the study, enabling them to make an informed decision about whether to participate or not. Eligible participants were provided with an information pack about the study containing a study invite letter and consent to contact form (Appendix E), an information sheet (Appendix F) and a copy of the consent form (Appendix G). The information sheet provided an outline of the purpose of the study and explained what was expected of them if they chose to participate. The information sheet also included a description of the interview topic areas and emphasised that this process was participant led (i.e. that participants had autonomy to decide which questions to answer and how much to say on each topic area). Potential participants were also encouraged to take at least 24 hours from receipt of the information pack before expressing their interest in the study, to allow sufficient time to consider the information received.

Steps were taken to try and ensure that potential participants did not feel coerced into participating. The voluntary nature of participation was emphasised in the information sheet and also reiterated verbally by the researcher prior to obtaining written consent. Potential participants were assured that their decision to participate would in no way affect the care and treatment they received from their NHS service. They were also assured that their own clinical psychologist would not be informed about their decision to participate or not.

Potential participants were only contacted once they had signed and returned the consent to contact form. The researcher then answered any questions, checked

that the potential participant had read and understood the information provided, and reconfirmed that they met the eligibility criteria. The researcher then arranged to meet the participant to complete the interview. Written consent was obtained immediately prior to commencement of the interview. The participant was given a copy of the signed consent form for their records.

2.3.3 Confidentiality and data protection

Participants were made aware of limits to confidentiality and data protection procedures prior to giving consent to participate in this study. This information was provided in the information sheet, and the researcher also took time to go through the details of this with potential participants prior to obtaining written consent.

Procedures were adopted to try and ensure confidentiality and protection of participant data as far as was practicably possible, within legislation (Data Protection Act, 1998) and professional good practice guidelines (British Psychological Society, 2009).

The researcher only had access to participant contact details (i.e., name and address) once they had provided written consent to share this information (see Appendix E). Participants were interviewed on a one-to-one basis, by the researcher. Participants were given the choice of being interviewed in a private clinic room at their local NHS memory clinic or in their home. If the participant chose to be interviewed in their home, a convenient time was arranged when privacy could be maintained and interruptions kept to a minimum.

Interviews were digitally audio-recorded and the data file was transferred onto a NHS password-encrypted memory stick as soon as possible after each

interview. The interview data file was then deleted from the audio recorder. Each interview was transcribed verbatim. Once the transcript had been checked for accuracy, the audio data file of the interview was deleted from the memory stick.

Each participant name was replaced with a unique alphanumeric code and any identifiable information (e.g., names and places) removed from the transcript, to ensure anonymity as far as possible. Alphanumeric codes did not contain any identifiable information (i.e., participant initials). Codes were allocated in order of participation. A list of codes and corresponding participant details was retained to allow the researcher to identify specific participant data, should the participant wish to withdraw from the study. This allowed the data to be identified and withdrawn, if necessary, until the point at which the report was written up. However, no participant asked to withdraw from the study.

Anonymised transcript data were saved on an NHS password-encrypted memory stick for use on other computers. The list of codes identifying the participants, consent forms and transcript data were stored securely and separately in locked filing cabinets at the University of East Anglia, accessible only to the researcher and research supervisor. All data will be kept for 10 years after the study has ended in line with the University of East Anglia's research policy, after which it will then be destroyed.

Participants were informed that anonymised excerpts from interviews may be included in the study write-up. Participants were also made aware that, should the researcher seek advice from the clinical supervisor and/or staff at the University of

East Anglia during the data analysis phase, only anonymised transcript data would be used during such discussions.

2.3.4 Potential risks/burdens

As participants were invited to openly discuss their experiences of undergoing a neuropsychological assessment for possible dementia, there was a risk that they might become distressed during the interview process.

This was addressed by providing potential participants with detailed information about the aims of the study, namely, what taking part would involve and the interviews topic areas covered, beforehand, so they could decide whether or not to participate. Participants were also assured that they could stop the interview at any time and did not have to answer any questions they did not want to. Plans were put in place should any participant become distressed. Had this happened, plans were to stop the session, provide the participant with the opportunity to briefly discuss these issues with the researcher, who is a trainee clinical psychologist, and, where appropriate, advise them to contact their own clinical team. All participants were debriefed at the end of the interview, providing them with an opportunity to reflect on and discuss the interview process, and ask any questions. Participants had already been provided with contact details if they wished to discuss the study further or make a complaint about the study conduct (see Appendix F).

Where interviews were carried out in the participant's home, the researcher adhered to the University Lone Researcher Policy: interviews were conducted within working hours and a buddy system was used to ensure researcher safety.

Clinical and research supervision was available for the researcher had any distress been experienced during the interview process.

2.4 Data Collection

2.4.1 Semi-structured interviews

Given this study aimed to explore personal experiences of neuropsychological assessment for possible dementia, it was important to use a method of data collection which elicited “detailed stories, thoughts and feelings from the participant” (Smith, et al., 2009, p.57). Semi-structured interviews are considered a preferable way of achieving this, as they allow participants freedom to describe their own experiences in their own way, whilst enabling the researcher to focus on particular topics of exploration (Hugh-Jones, & Gibson, 2012).

2.4.1.1 Interview schedule. An interview schedule was developed to guide the interview process (Appendix H). Interview topics were informed by the study research questions. The question structure was developed with reference to IPA interview guidelines (Smith & Osborn, 2008) and following discussions with the clinical supervisor. Questions were constructed to be sufficiently open-ended to allow participants freedom to describe their own experience of neuropsychological assessment for possible dementia, whilst allowing the researcher to investigate areas of interest relevant to the study research questions.

The schedule comprised four open questions intended to elicit discussion about identity, emotional response to neuropsychological assessment and methods of coping. A broad general question was also selected to initiate the interview process.

This was intended to encourage participants to take a lead role in the interview and describe their own experiences in their own way. This approach is consistent with the phenomenological epistemological perspective, that “reality” exists in peoples’ lived experiences, which can be accessed by interpreting the language used to describe those experiences. Therefore, it was considered important to encourage participants to express themselves freely from the outset, with the researcher listening and following up interesting areas of discussion to be explored further. The researcher was also flexible in how the interview schedule was used in each interview, in response to participant needs. Research has shown that interviewer involvement typically varies across interviews, with some participants requiring more guidance than others (Howitt & Cramer, 2011). Adopting a sensitive, flexible approach is particularly relevant when interviewing people with dementia, who may require increased response time and/or further prompts as a result of cognitive deficits which can impact on their ability to organise and express their ideas (Beuscher & Grando, 2009). Therefore, additional prompts were identified beforehand, in case the participant required further guidance.

The main aim throughout was to use methods to generate data, which primarily reflected participants’ views and experiences, rather than the researcher constraining the process by imposing their views and assumptions on the participant (Smith et al., 2009).

2.4.1.2 Interview pilot. The initial interview was used as a pilot, primarily to evaluate the effectiveness of the interview schedule and to reflect on the interactional process between the researcher and participant. The most important

aspect of this study was to develop an in-depth understanding of personal experiences of neuropsychological assessment for possible dementia. Therefore, the researcher considered it vital that interviewees felt comfortable and empowered to express their views, and that the interview process was primarily participant led. The researcher was also mindful of being a novice researcher and more used to conducting clinical interviews. Reflecting on the interview process enabled the researcher to notice helpful and unhelpful techniques (i.e. allowing sufficient time for the participants to think and respond, noticing where topics or areas of interest were not followed up). The researcher also found that using the initial open question and then following the flow of the participant resulted in a more rich subjective account of the participants' experiences.

Interviews were transcribed verbatim and analysed using IPA (see section 2.6 for further detail).

2.5 Procedure

Once consent to share details (see Appendix E) had been received, the researcher liaised with participants directly. The researcher contacted the participants to discuss the research project further. Participants were given an opportunity to ask questions about the study. If the participant wanted to participate, then the researcher arranged a venue and date/time to complete the interview. The researcher offered to meet the participant either at their local NHS memory clinic, or at the participant's home, whichever was most convenient for the participant. Three

participants were interviewed at home, and 5 participants were interviewed at their NHS clinic.

On meeting the participant, the researcher checked that they had read, and understood the contents of the information sheet (Appendix F) and consent form (Appendix G), and answered any questions about the study. The researcher confirmed that the participant still met the eligibility criteria. The researcher reminded the participant that their decision to participate was completely voluntary and that they could withdraw their consent at any time, without having to provide a reason for this decision. The researcher confirmed whether the participant wanted to continue before obtaining written consent. If they wanted to continue with the interview, the participant was asked to complete and sign two copies of the consent form (Appendix G). The participant was given one copy to keep, and the researcher retained the other copy. Once consent had been given, the interview and audio recording process commenced. Participants were encouraged to speak about their experiences of undergoing a neuropsychological assessment for possible dementia in their own way. They were also made aware that they could take a break during the interview process, stop at any time, and did not have to answer any questions they did not want to. The interview schedule (Appendix H) was used as a guide to facilitate open discussion. Each interview was audio-recorded and lasted between 30 and 60 minutes duration. After the final question had been answered, the researcher asked the participant if they would like to add any further comments before the interview ended. Once the interview process had finished, the audio recording was stopped. Each participant was then debriefed. They were asked about their

experience of being interviewed and given the opportunity to ask any questions about the study. Participants were also asked if they would like to be sent a summary of the research findings once the report has been written up. Each participant's GP was advised that they had taken part in the current study (see Appendix I for example of GP letter).

2.6 Data Analysis

Interview data were analysed using IPA. As the core focus of IPA is in exploring and seeking to understand subjective experiences and how participants attempt to make sense of their experiences, analysis is predominantly “bottom-up” whereby themes emerge from participants' accounts. The analytic process in this study was informed by guidelines outlined by Smith et al. (2009). They describe a common set of processes in which data is analysed at both an idiographic and nomothetic level. The process adopted in this study is described in detail below.

2.6.1 Transcription process

The transcription process commenced after all interviews had been completed. Interviews were transcribed verbatim, and features of social interaction deemed important in representing how participants made sense of their experiences were also recorded (i.e., tone of voice, pauses, emphasising certain words). Any identifiable information (i.e., names, places etc.) was removed to ensure participant anonymity.

2.6.2 Individual case analysis

Analysis commenced after all the interviews had been transcribed. In keeping with the idiographic focus of IPA, each transcript was analysed in detail, on an individual basis, before comparisons were made across cases. The process of analysis was cyclical and the researcher proceeded through a number of iterative steps, which are described in detail below.

2.6.2.1 Detailed reading of the transcript. Having listened to the audio recording at length and generated a verbatim transcript, the researcher then used a paper copy of the transcript for analysis. The researcher read through the transcript in great detail, several times over, in order to bring the participant's individual experience into focus and for the researcher to feel immersed in the participant's experience of their neuropsychological assessment.

2.6.2.2 Initial exploratory coding. During this reading process, the researcher conducted a word-by-word, line-by-line review. The researcher noted down comments, ideas, thoughts and reflections in the right hand margin. At this stage, analysis was predominantly descriptive allowing the researcher to begin to identify salient points and themes within the text. The transcript was reviewed several times to incorporate different types of coding, moving from descriptive to include linguistic commentary, thus exploring specific use of language. Finally, more interpretative noting was used to try and make sense of meaning of participant's experiences. Participant comments that related to these initial ideas were also highlighted, forming an audit trail explaining how the analysis and conclusions were reached (example of coded transcript shown in Appendix J).

2.6.2.3 Developing emergent themes. The researcher then read through the transcript again and transformed the initial notes into higher-level themes or categories, which were recorded in the left hand margin. This process was predominantly interpretative and the researcher aimed to psychologically conceptualise the participant's experience, whilst remaining grounded in the detail of the participant's narrative (see Appendix J).

2.6.2.4 Connecting themes. Emergent themes were then listed chronologically and reviewed to identify any connections between themes. Where appropriate, connected themes were organised into super-ordinate categories. These categories were cross-referenced back to the original text, to ensure that interpretations were valid. Super-ordinate, sub-ordinate and corresponding text extracts were tabulated, generating a summary of the analysis process and conclusions made (example shown in Appendix K). This core set of themes was used to orient analysis of subsequent transcripts, however the researcher also remained open to identifying new themes in the other transcripts.

2.6.3 Cross case analysis

After all interviews had been analysed individually, the researcher compared themes across interviews. Tabulated themes from each transcript were compared to identify any convergence/divergence across themes. A number of super-ordinate themes were amalgamated to create a final set of four shared super-ordinate themes, each containing a number of sub-ordinate themes. A master list of group themes are shown in Appendix L, and illustrated graphically in Figure one (see section 3.3).

As the researcher was a novice to this approach, supervision was gained from one supervisor experienced in qualitative research methods, and from another experienced in IPA. The researcher also attended a two-day IPA workshop in order to develop skills in IPA.

During the analysis process, supervision sessions were spent reviewing exploratory coding and emergent themes within transcripts to check the validity of researcher's interpretations in relation to the participant's narrative account.

2.7 Reflexivity

In qualitative research, it is acknowledged that the researcher's beliefs and assumptions will have an influence on data collection and analysis (Henwood & Nicolson, 1995). Rather than seeking to control this "researcher bias" as with quantitative research, subjectivity is routinely identified and acknowledged through a process of reflexivity. One way of achieving this is to be open and clear about own assumptions and beliefs from the outset, thus "owning one's perspective" (Elliott et al., 1999). In the next section the researcher provides a personal statement with these aims in mind. Further reflections on the method are included in section 3.4 and a more detailed discussion about researcher reflexivity is provided in section 4.4.1.5.

2.7.1 Personal statement

I am a white British woman in my thirties and am currently studying as a trainee clinical psychologist at the University of East Anglia. I have lived in the East of England all my life. I am married and do not yet have any children. I have chosen to live within a rural setting and value the inclusiveness of being within a small

community. I returned to study as a mature student having worked within a commercial business environment for a number of years before this. I chose to change direction, as I wanted to pursue a career that felt more personally meaningful rather than focused purely on generating profit for business.

I have worked within the field of psychology for the past 5 years. Prior to clinical training, I worked as an assistant psychologist in a brain injury rehabilitation service. As part of my role, I administered neuropsychological assessments with the purpose of determining cognitive strengths and difficulties to inform individualised rehabilitation programmes. I observed people's distress at being assessed and learnt how people valued receiving honest, constructive feedback and having the opportunity to express their views. I heard how people often felt stigmatised and marginalised, as though they had become "invisible" in society after their brain injury, despite them wanting to take an active role in rebuilding their lives. I became interested in thinking about ways that those underrepresented in both society and research might have their views heard.

During clinical training, I worked in a memory clinic service conducting neuropsychological assessments with the purpose of assisting in diagnosing possible dementia. I observed a range of responses in people going through this process. Some were distressed at being assessed, feeling like they were "back at school" and waiting to hear "the dreaded news", whereas for others, the process appeared more positive in confirming their own self-appraisal and allowing them to make plans for the future. I was struck by these differences and wondered what factors influenced their beliefs/appraisals.

My ideas for the current study developed from observations and unanswered questions that arose from these experiences. From a personal perspective, I have not experienced a loved one going through this process as none of my family has been assessed for possible dementia.

In terms of epistemology, I disagree with pure positivist principles; that there is a true reality that can be objectively measured. Instead, I consider myself more aligned with phenomenological and constructivist ideas, which view reality as subjective, constructed from life experiences and represented internally. This may also be viewed as a critical realist perspective.

From my experiences and review of the literature, I wondered if people's experiences of neuropsychological assessment for possible dementia would vary quite considerably depending on beliefs and assumptions about this process. I also wondered whether people who chose to share the experiences might see the process in a more positive light than those who did not participate.

3.0 Results

3.1 Overview

This chapter aims to provide a rich narrative account of the participants lived experience of undergoing a neuropsychological assessment for possible dementia, as seen through the lens of the researcher. Both shared and idiographic aspects of the participant's experiences will be presented and explored. The participants "shared experience" is presented and discussed in relation to superordinate and subordinate themes that emerged from the analytic process (outlined in Chapter 2).

Each superordinate and subordinate theme will be presented and explored in detail with verbatim extracts from participant interviews provided to support the researcher's interpretation of the participants' experiences. Individual experiences will be explored within each theme. Commonalities and differences between participants' experiences will also be discussed.

As a core focus of IPA is to recognise and value an individual's lived experience, this chapter will begin by presenting a detailed descriptive summary of each participant in order to help the reader hold the person in mind when reading the narrative account of the analysis.

3.2 Participants: Descriptive Summary

Information about each person who participated in this study is provided below. This information was largely drawn from discussions with the participant during the interview as well as from demographic data (see section 2.2.4) collected

prior to interview. Pseudonyms have been used to ensure that participant anonymity is maintained.

Jean: is a 79 year old white British woman who is retired and lives alone. Her husband passed away several years ago. She described herself as an inquisitive person who loves to read and keep herself busy. She lives close to her family and enjoys spending time with them. Remaining independent is important to her. Jean initiated the assessment after she became concerned about her memory deteriorating and forgetting the “right” words. After completing her neuropsychological assessment Jean was given a diagnosis of Mild Cognitive Impairment and was recommended to complete a 9-12 month re-assessment follow-up. She was interviewed two months after receiving her initial assessment results.

Zeena: is a 65 year old Asian African woman who lives with her husband and is retired. She is active in her local community and enjoys supporting and helping others. She described herself as a “fighter” having overcome adversity as an immigrant many years ago. Her family is important to her. Zeena asked for an assessment at the memory clinic because she noticed problems with her memory and because she has a family history of Alzheimer’s disease. The results from her neuropsychological assessment were inconclusive and a re-assessment was recommended in 9-12 months time. She was interviewed two months after completing her neuropsychological assessment.

Terry: is a 67 year old white British man and lives with his wife and two teenage children. He is retired and recently gave up some voluntary work after experiencing problems with his memory, he now spends a lot of time at home alone.

Terry visited his GP after feeling concerned about his memory and asked to be referred for assessment. He described himself as an active person although he felt this had changed recently. Following his neuropsychological assessment, Terry was diagnosed with Alzheimer's Disease. He was interviewed two months after completing his neuropsychological assessment.

Derek: is a 64 year old white British man who is retired and lives with his wife and daughter. He described himself as an active person who likes to understand the reasons why things are happening and how they work. He had previously had psychological therapy for trauma some years ago. He visited his GP after feeling concerned about "short-term" memory problems and also because he has a family history of dementia. His neuropsychological assessment results suggested no evidence of dementia and his difficulties were attributed to psychological factors. He was interviewed one month after he had completed his neuropsychological assessment.

David: is a 66 year old white British man who is retired and lives with his wife. He talked about coming from a high achieving, academic background and described himself as having always been capable and always being able to solve problems. David had sought an "investigation" of his cognitive functioning after experiencing memory and word findings difficulties, with a view of wanting to "resolve" these. He has a significant family history of dementia. David had decided not to tell others about his neuropsychological assessment and talked about feeling worried about how others might view him. David was diagnosed with Alzheimer's disease and was interviewed two months after he received his diagnosis.

Mick: is a 60 year old white British man who currently lives alone. He had to give up work due to physical health difficulties. Mick described himself as a social person, with his family being extremely important to him. He reported feeling concerned about his memory and getting confused about where he was. Mick had been receiving psychological therapy for trauma when he was referred for a neuropsychological assessment. Mick was concerned that his memory problems might mean he had dementia. The outcome of his neuropsychological assessment indicated that his cognitive difficulties were likely to be influenced by psychological factors. He was interviewed two months after completing his neuropsychological assessment.

Janet: is a 65 year old white British woman, who is retired and lives with her husband. She describes herself as quite an anxious person and prefers to have others around her. She visited her GP after becoming concerned about her memory: forgetting what she needed to do and what people had said in conversations, and was worried that she had dementia. Her neuropsychological assessment outcome was inconclusive and she was recommended to complete a re-assessment in 9-12 months time. Janet was interviewed three months after completing her neuropsychological assessment.

Eric: is a 68 year old white British man who lives with his wife and is retired. His family live close by and he enjoys spending time with his children and grandchildren. Eric described himself as a “passionate activist” wanting to resolve grievances for others. Until recently had been actively involved in advising local organisations however he had given this up as he felt he could not “cut it” anymore.

Eric has a number of physical health conditions and became concerned that he might have dementia after experiencing memory problems, word finding difficulties and getting lost. He asked for a memory assessment himself. At the end of the neuropsychological assessment process Eric was told he did not have dementia. He was interviewed one month after receiving these results.

3.3 Superordinate Themes

Overall, participants described their neuropsychological assessment experience for possible dementia in terms of a journey, broadly characterised by uncertainty and the search to make sense of, and manage, that uncertainty. Whilst the neuropsychological assessment itself appeared to represent the mechanism by which participants tried to make sense of what was happening to them, it formed part of a much wider conceptualisation of their overall assessment journey. Within the context of uncertainty and meaning making, four interrelated superordinate themes containing nine subordinate themes emerged, which encapsulated different aspects of this “shared” experience. The superordinate themes that emerged from analysis of the participant’s experiences were: (i) “Things aren’t right: what’s wrong with me?”, which represented pre-neuropsychological assessment experiences, (ii) “Testing by name, testing by nature”, (iii) “Professional roles: different sides of the same coin”, which represented neuropsychological assessment experiences, and (iv) “Finding out....”, which represented post-neuropsychological assessment experiences.

Superordinate and related subordinate themes are illustrated diagrammatically in Figure one and will be presented and discussed in detail below. Figure one is intended to represent how the themes are interrelated rather than demonstrating or indexing an amount or intensity of overlap.

In the narrative account that follows, extracts have been selected that best represent the participants' shared experiences. Selections of individuals' views have also been interpreted to allow the reader to gain further insight into idiosyncratic experiences. A Table illustrating the presence of each theme within participants' accounts has also been included (see Appendix M)

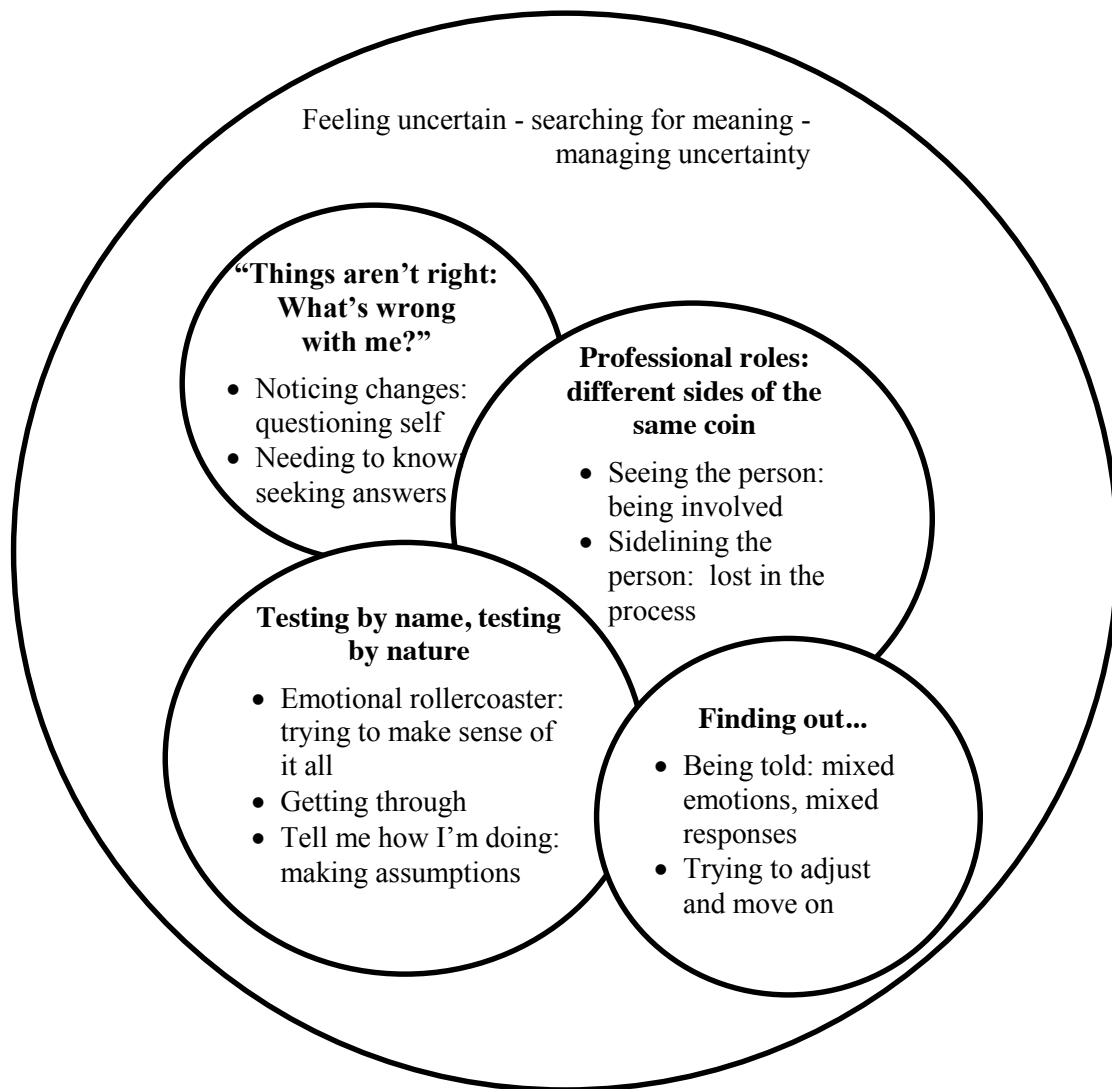


Figure 1: Themes representing participants’ experiences of neuropsychological assessment for possible dementia

3.3.1 “Things aren’t right, what’s wrong with me?”

Integral to participants’ neuropsychological assessment experience was the journey that took them there. Jean’s comments seem to capture the participants’ shared experience:

“well I...I...felt certain things that were...err...there were CHANGES...which triggered the idea of me going there...you know I thought well “things aren’t right”, you know, well “what...what’s wrong with me?” (Jean, p. 14: lines 220-223)

Here, Jean talks about experiencing a sense of feeling within herself that somehow things had changed and that this was not right, or perhaps indicating to her that something was intrinsically wrong with her. Her hesitant speech has been interpreted as reflecting the uncertainty that she felt inside herself, that things had changed but that she did not really understand why. It appears that, for Jean, this feeling of incongruent self triggered a need to investigate this further.

All participants talked about noticing changes in themselves at odds with their normal sense of self, resulting in an acute and inescapable awareness that left them concerned that something was wrong with them. Their awareness of a discrepancy between their prior sense of self and current experience of self appeared to trigger a need to attempt to resolve this self-discrepancy resulting in them trying to understand what was happening to them by seeking answers from others.

Each of the subordinate themes: “noticing changes” and “seeking answers” will be discussed in more detail below.

3.3.1.1 Noticing changes: questioning self. All participants described how they had noticed changes in themselves and how certain normal, everyday tasks had become more difficult, resulting in them questioning themselves and what was happening to them. Many experienced these difficulties as threatening their self-identity. All participants spoke about trying to make sense of this uncertainty; many wondered if their mental state was deteriorating and some expressed their concerns that changes might be indicative of dementia. Participants seemed to find this an emotional time, with many feeling frustrated and worried:

“I was very concerned about my memory, forgetting things...

FRUSTRATING...you know, erm...I felt worried very worried...is it me...what’s this (sighs) (Janet, p. 4: lines 49-51)

Here Janet describes her emotional turmoil and sense of confusion in trying to make sense of her memory problems, how she felt frustrated but also worried that perhaps something was wrong. There is also a sense of her questioning herself and in the interview it felt as though she almost didn’t know what to think or whether to trust her own perception of herself as changing.

For others they felt sure about noticing changes but unsure about why this was happening. When recollecting how he had initially noticed changes in himself, Terry talked about how he had planned to go into town as normal

following the same route he always took and then “found” himself in a different place altogether:

“about 6/7 months ago now I think, going to [place] and I’d turned around at [place] on the [place] road, why I went there I didn’t know”
(Terry, p. 6: lines 80-81)

Here, he described the realisation that he is not where he wanted to be and appeared dumbfounded as to why he went there. This seems to show how Terry felt uncertain about his own actions and was questioning what he was doing, as though this happened without him realising or perhaps him not feeling in control of himself. Terry also talked in detail about another situation when he drove the wrong way and his wife noticed and questioned him, perhaps highlighting that something was not quite right:

“I was doing silly things, she’d go, do you know where [place] is in [place] well you go from there into town and normally drive straight down [name] road and [place] I’d go via [name] road and we’d get down [name] road she’d say erm “are you alright” and I’d say “yeah”, she’d say “where are we going” and I’d say “town”, then I’d realise what I’d done, and I ish just turn around and say to her “I thought we’d go a different way today”, cos I’d realised my mistake” (Terry, p. 5/6: lines 73-79)

In describing himself doing “silly things” this may be interpreted as Terry perhaps seeing himself as lacking judgment or not being in control, for example doing things without reason. During the interview it seemed as though Terry also experienced this as infantilising. Terry appears to feel embarrassed at not knowing what he was doing and attempts to conceal this “mistake” from his wife. Without a logical explanation for his experiences Terry attributes his actions to a changing internal state, wondering if perhaps he was losing his intellect:

“I thought I was going stupid (pause)” (Terry, p. 6: line 83)

This felt like a poignant moment in the interview where Terry paused before moving on. This was interpreted as holding a powerful meaning for Terry, as though perhaps he felt he was somehow losing himself.

Other participants shared similar experiences with Terry indicating a shared experience of feeling confused about themselves:

“you know we’d go out somewhere and I’d know we should be going in a certain direction but err...but I didn’t know where I was going to go or...and I’d end up...” (Eric, p. 1: lines 9-11)

In this excerpt, Eric talks about how, in his own mind, he was certain of his plans but the reality turned out somewhat different, as though he was not in control.

His hesitant speaking and unsaid words about his actual destination have been interpreted as reflecting his confusion over what was happening and where he was going.

For Eric, some of the other changes and difficulties he experienced were extremely personal to him, threatening his self identity:

“I’d be in there trying to grasp at words, you know, I...I’ve got a fairly large vocabulary but I couldn’t get it...kept missing...and couldn’t put over what I was trying to put over in a...a proper manner really, so it was...and I kept forgetting things you know just crazy really” (Eric, p. 1-2: lines 12-16)

Communicating effectively was important to Eric. He had been a panel member of a local organisation committee for several years and prided himself on being able to speak up and represent the views of others. In the excerpt above, Eric describes losing his ability to use language in a way he would expect of himself. The excerpt above depicts his increasing struggle and fight to try and find words, which he believes are there somewhere but which he can no longer reach. This seems to reflect his confusion over his identity and loss of trust in himself, as though something out of his control is happening to him. Stating that he has *“a fairly large vocabulary”* in the present tense has been interpreted as Eric trying to prove that he is still capable, and perhaps trying to hold on to a past view of himself.

Zeena also talked about how forgetting impacted on her self identity:

“when we are doing the prayers we are asked to come in the front...in front of whatever number of people come, there could be...sometimes there could be 50 people 60 people, twice I made mistakes, which in my life I have never made a mistake” (Zeena, p. 4: lines 54-57)

During the interview Zeena had talked about how her religion was integral to her identity. This extract illustrates how something that she normally did without even thinking (i.e., saying her prayers) was suddenly compromised by her memory difficulties. This was a great shock to Zeena and she felt embarrassed that others might think she was not a ‘good Muslim’:

“I think well “what do they think”, you know, “will they think bad of me”, you know, cos I forget my prayers” (Zeena p. 4, lines 59-61)

Not being in control was central to many participants’ descriptions about how they felt after noticing and experiencing difficulties with their memory and other abilities. Mick’s experiences seemed to feel totally alien to him:

“it was like it wasn’t doing what it should...thinking things...forgetting things...” (Mick, p. 5, lines 67-68)

Here, it is interesting how Mick uses the word “it” when talking about doing things differently from how he had expected. There is a sense in his use of language that he feels disconnected from what is going on, perhaps indicating that he found it difficult to associate what he was doing with his perception of himself. For Mick, this sense of not feeling in control was frightening for him and he went on to describe how feeling uncertain about himself negatively affected his self confidence and left him feeling like his actions were no longer predictable:

“I didn’t feel safe with meself...” (Mick, p.4, line 60)

For Derek, experiencing problems with his memory had added significance given his family history of dementia.

“I felt my short-term memory was failing and my history have...my family has a history of that sort of things...parents... erm...and so I became concerned about that” (Derek, p.1, lines 3-6)

Whilst he doesn’t say the word “dementia”, he alludes to this in relating his experiences with his family history. Perhaps for Derek, the thought of having dementia is too difficult to comprehend, yet in this extract his concern about having dementia is implied, indicating that this is perhaps how he made sense of his experiences. The researcher also wondered if, in noticing his difficulties and relating

his experiences to his family history Derek felt a sense of inevitability that he too would develop dementia.

Whilst most participants tried to make sense of their difficulties by comparing their “current self” to their “past self” Zeena made comparisons between herself and others:

“I...I personally felt why why am I forgetting things, all of my friends and everybody’s fine, that why was that happening to me, what it going on, you know, why is it happening to me” (Zeena, p. 3, lines 48-50)

This seems to reflect how, for Zeena, she feels different to others around her and is using others’ level of functioning as a benchmark to determine whether her difficulties with memory are normal or not. There is also a sense of injustice that she had been forgetting, when others had not.

3.3.1.2 Needing to know: seeking answers. This subordinate theme reflects how participants sought to make sense of the changes they had noticed in themselves by seeking answers from professionals. Many participants described the battle they had in trying to convince their GP to refer them to the memory clinic for further investigation. On achieving their aim there was also a sense of tension between wanting to know, as a means of resolving their inner conflict, and fearing what might be discovered (i.e., being diagnosed with a dementia), which resulted in many feeling apprehensive about the prospect of being assessed at the memory clinic.

Most of the participants talked about wanting to find out if there was ‘something wrong with them’ although this desire for answers was often tempered with a sense of trepidation. Here Eric describes how he felt:

“and I wanted to find out, really...I wanted to find out if there was anything...” (Eric, p. 18: lines 313-314)

This seems to indicate that it was important for Eric to make sense of his difficulties and find out what was happening to him. In the interview, the tone of his voice when saying the word “really” seemed to suggest that Eric was trying to convince himself that undergoing an assessment was the right thing to do, despite perhaps feeling apprehensive at the prospect of this. In this dialogue he stops before completing the sentence, which was interpreted as him perhaps not wanting to think about what the “anything” might be. For Janet, she was definite about her need to understand changes she had noticed in herself:

“I...I REALLY needed to know, you know, what it was...what was like erm happening to me...it was IMPORTANT” (Janet, p. 1: lines 4-6)

In the interview Janet emphasised the words “REALLY” and “IMPORTANT”. The researcher experienced this, as indicating that, for Janet, making sense of her difficulties was a matter of urgency and that finding out was

important; perhaps due to the potential consequences of a diagnostic outcome. Janet went on to discuss the meaning of the assessment for her:

“felt that this was...going...to...tell...me...whether I had dementia or not...you know I thought that THIS WOULD be the final thing that make all the difference to the rest of my life” (Janet, p. 4, lines 52-54)

Here, Janet highlights just how important she sees the neuropsychological assessment is to the rest of her life, indicating that her expectations are that she will find out a definitive answer about whether or not she has dementia.

Many of the participants described how “seeking answers” was not a straightforward process and they had to persist in asking to be assessed. David talked about how he had raised his concerns about his memory difficulties, with his GP, several times before being referred:

“but I had mentioned it to various GPs that I was concerned about my memory...but nothing happened for some time...” (David, p. 2, lines 22-24)

Jean also described how she was keen to make sense of her difficulties but her initial concerns were dismissed by her GP as being normal:

“and I think...you know “let’s find out much...” in other words “let’s investigate”, I told my doctor that I worried about my memory and she said, well...as most people say, “oh well of course we do, I always forget names half way through” and all the rest of it, BUT it’s not so much the names, it’s...it’s more than that and I realised that something wasn’t quite right in that line...in that vein...and therefore let...I TOLD her, and she said “well I will then refer you” (Jean, p. 14: lines 225-233)

This extract highlights how, for Jean, her internal experience of her difficulties felt far from normal and she persisted in asking for an explanation. There is also a sense here that perhaps Jean felt her GP remained reluctant to refer her. For Zeena she described having to “fight” to be assessed:

“well I had to fight to come here, that’s true, like err I remember 3 years ago I had been telling...I was telling my doctor, you know, that I forget things, you know, so...at least 3 or 4 times I did mention and the...they didn’t take notice of it...” (Zeena, p. 6, lines 105-108)

Here again, there is a sense that Zeena felt her concerns about her memory had not been addressed or taken seriously.

Although participants wanted to understand what was wrong with them there was also a sense of trepidation and worry about what might happen during the neuropsychological assessment, and what the outcome might be. As Jean put it:

“I thought “oh dear”, you know...ummm...”what are they going to find out about me, what are they going to ask me” (Jean, p. 24, lines 413-415)

Jean had been talking about wondering what the neuropsychological assessment might discover. Here there is a sense of her considering the reality of what might happen as though perhaps something might be uncovered about her that could then no longer be hidden. Mick also described similar worries to Jean:

“worrying about what would happen...in the end...but I was also worrying about the questions...” (Mick, p. 1, lines 5-7)

It is interesting to consider how, for both Jean and Mick, they highlight their concerns about the outcome of their neuropsychological assessment, before questioning what might happen in the assessment itself. The order in which they discussed their worries was considered meaningful, perhaps indicating that underneath it all, their main concern was with the outcome over everything else.

3.3.2 Testing by name, testing by nature

The second superordinate theme, “Testing by name testing by nature” captures how participants experienced and made sense of the neuropsychological assessment, itself and depicts how intense this process was for them. For participants, the neuropsychological assessment was an emotional experience characterised by feelings of loss, frustration and anxiety, with many left wondering how they had performed. Participants used a range of different strategies to help manage and cope with getting through the neuropsychological assessment process.

In the absence of receiving feedback during the neuropsychological assessment, participants sought to make sense of their ability by monitoring their performance and making assumptions, resulting in many fearing the worst. Waiting to receive results of their neuropsychological assessment exacerbated participants’ anxieties and maintained their uncertainty about themselves. Each of the subordinate themes “emotional rollercoaster”, “getting through” and “tell me how I’m doing” will be explored in detail below:

3.3.2.1 Emotional rollercoaster: trying to make sense of it all. This subtheme captures how emotionally intense the neuropsychological assessment experience was for the majority of participants, and how they endeavored to make sense of their experiences. For many, the process of being tested appeared to highlight their inabilities resulting in them feeling a sense of loss, frustration, inadequacy, confusion and anxiety, with some also finding the process isolating. The neuropsychological tests themselves appeared strange and confusing to many, with some participants questioning the usefulness of these assessments. There was also a

sense that many participants felt ill prepared for the emotional reality of being assessed despite receiving a detailed procedural explanation.

The emotional intensity of the neuropsychological assessment procedure permeated the majority of participants' accounts. For some, their neuropsychological experience was characterised by a series of highs and lows:

“oh I love it when there's tests that I can do...all the shapes and physical things, but erm, bringing out random err...animals beginning with A, B oh I think it was ANIMALS names of animals, as many as you can in a couple of minutes, and I was working...working through the alphabet trying to do it, but when think of...of that...that is very frustrating” (David, p. 9, lines 136-142)

This excerpt demonstrates how, for David, his emotional experience was influenced by his perceived performance; great when things were going well and frustrating when they were not. The changing flow of this passage seems to reflect the uncertainty of his experience, moving from being easy and fluid to becoming more hesitant and difficult. There is also a sense here that despite his efforts David just couldn't complete the task, perhaps highlighting to David that his abilities had deteriorated, therefore compounding his frustration. David's feelings of frustration resonated throughout much of his interview and are clearly shown here:

“Frustrating, really frustrating, you know I could get very frustrated when I get some of these tests that I’m not very good at” (David, p. 9, lines 134-136)

David uses a form of the word “frustration” three times in this short sentence highlighting the intensity and salience of these feelings. Speaking in the present and past tense perhaps suggests that his past feelings of frustration still remain today. David had previously talked about coming from a high achieving background and was used to doing well. His experiences of not meeting his expectations were interpreted as significant for David, representing a threat to his self-identity.

Jean shared similar experiences with David. Here she describes how her enjoyment quickly changed to frustration and confusion when she was confronted with her inability:

“enjoyed that, because almost...I think that’s the one...almost got...I got...I was quite good on that, in fact very good on that particular thing, but then another one, I WASN’T, just frustrating...and I couldn’t understand why” (Jean, p. 18, lines 303-306)

There is a sense in Jean’s emphasis of the word “WASN’T” that this experience occurred abruptly and unexpectedly, suggesting that perhaps the neuropsychological assessment process highlighted difficulties she was unaware of, resulting in her questioning herself. This was a common theme for Jean and other

participants and throughout her interview she talked of her disbelief in not being able to do tasks that she perceived as simple and straightforward:

“I could not BELIEVE, I mean there’s a lot of things I was aware of that I could or couldn’t do, I COULD NOT believe that I... that I could not copy THE most SIMPLE...the...the box, (Jean, p. 2, lines 16-19)

This passage has been interpreted as highlighting Jean’s sense of exasperation at being confronted with an unfamiliar “current self”. There is a sense here that Jean thought she understood herself and that the neuropsychological assessment process revealed some unwanted truths, therefore threatening her sense of self.

For others, disbelief was coupled with anxiety about whether their perceived difficulties were indicative of a serious underlying problem.

“she did give me a story for about 3 or 4 minutes and and which I had to remember and say the story again, you know, I couldn’t do it...found that very hard you know, worried you know, is this my memory...is it bad you know, I don’t know,” (Zeena, p.1-2, lines 12-16)

During the interview Zeena had described herself as a resourceful person, used to overcoming adversity and difficult situations. Yet here, there appears to be a

sense of finality in her statement as though this task was impossible to her. This impossibility seems to have triggered a sense of worry and confusion for Zeena with her doubting her memory ability and wondering if this was indicative of bad news to come.

Eric shared similar anxieties with Zeena and described the whole neuropsychological assessment process as extremely stressful:

“I felt quite fraught when I went out of that one and that one...I felt awful, I sat there and I just couldn’t do the lot of it you know, I kept thinking you know “what’s this all about?” “that isn’t good” (Eric, p. 4, lines 65-68)

Eric seemed to perceive that he couldn’t complete any of the tasks, which left him feeling confused about the process and predicting that perhaps the outcome would be bad news. Eric’s perception of his experience and ability is interesting as he was later told that he did not have dementia, indicating that his performance was not impaired. The researcher wondered if there was something about Eric’s experience of the neuropsychological assessment process that led him to reach those conclusions.

In contrast to other participants’ experiences, Mick described feeling emotionless:

“as I remember...it was like I’d got no feelings at all...maybe a kina whadya call it...numbness...like nothing...” (Mick, p.6-7, lines 90-91)

This excerpt seems to indicate that Mick felt emotionally disconnected from the neuropsychological assessment process. Earlier on in his interview Mick had highlighted how significant the neuropsychological assessment was for him and his concerns that he might “*get sectioned*” (Mick, p. 4, line 58). The researcher wondered whether for Mick being emotionally disconnected protected him from engaging with his fears.

Several of the participants experienced the neuropsychological assessment as an isolating experience as they were unable to draw on the support of others, leaving them feeling all alone:

“I’m used to working as a team, you know rather than doing something on my own so...that was a horrible feeling” (Janet, p.5, lines 77-79)

For Janet, attending the neuropsychological assessment sessions alone seemed to provoke intense anxiety as she was used to spending much of her time with her husband, facing challenges together. When talking with Janet, there was a sense that in facing this challenge alone she was not only concerned about what the outcome of the neuropsychological assessment might be but also about her ability to manage such a significant thing on her own, and without her husband.

Eric shared a similar experience to Janet's:

“you then are all of a sudden...all of a sudden you are alone...you know, and you're on your own and you've got no support and nothing, you just...(pause)...you've gotta go through it yourself” (Eric, p.17, lines 299-302)

This felt like a poignant moment for Eric in the interview and there was a sense that perhaps Eric was unprepared for just how isolating the neuropsychological assessment experience would be. His use of the word “sudden” twice has been interpreted as emphasising his surprise. Eric had described himself as a sociable person who normally discussed concerns and issues with his wife and family, however here he was unable to use his normal coping strategy and draw on support from others (i.e., the psychologist assessing him), which was difficult for him.

In addition to feeling confused about their performance, many participants appeared confused by the type of tests used. There was a sense amongst the participants that the tests did not represent everyday abilities, which led some to question the usefulness of the tasks. Here Eric describes his how he felt about the neuropsychological assessments:

“there were things like putting dice together in different pictures, it's daft to me, you know, I used to think oh cripe I can't be doing with

it, you know, where as research into the first world war...I sit and read forever more...and err...that to me is err...you know and it stays in the memory funny enough...but THAT STUFF” (Eric, p. 6-7, lines 105-110)

There is a sense here in the way Eric describes the tests as being “*daft to me*” that the tests seemed silly and not relevant to his real life. Eric talks about how his memory is good in certain situations suggesting that perhaps he feels like the neuropsychological tests aren’t measuring the right thing. This was interpreted as Eric trying to attribute difficulties to an external source, and the researcher wondered if this enabled him to preserve his self-concept.

Derek also describes finding it difficult to make sense of the different neuropsychological assessments used:

“I...I...I...found it very difficult...because erm...err...I didn’t really know what was going on and...and...I...I didn’t know how I was going on” (Derek, p. 10, lines 169-171)

Derek had described himself as a practical problem solver and in making sense of his experience, it was important for him to understand the reasons why things were happening and how they worked. This excerpt highlights Derek’s uncertainty about what was happening. Being unable to make sense of the different

neuropsychological tests translated into Derek being unable to make sense of himself and how he was doing, leaving him feeling confused and frustrated.

Finally, when talking about the intensity of their emotional experiences, it became evident that despite being given a detailed explanation of the neuropsychological assessment process and procedures, many participants felt completely unprepared for the “reality” of their experience. Janet’s comments seem to capture this shared view:

“maybe I did know what it was...you know...but when it happened cos well...because it had been explained to me, went through what was gonna happ...wha ..what it would entail...but erm...doing it...doing it...it, I really felt erm...that you know ...that it was a REAL TEST (sighs)... ” (Janet, p. 3, lines 37-41)

In this excerpt there is a real sense of conflict in how Janet is trying to make sense of her understanding and experience of the neuropsychological assessment process. On the one hand, Janet talks about being told what the neuropsychological assessment would “*entail*”, suggesting that the procedure was explained. However, on the other hand, it seems clear that the reality was very different perhaps highlighting the discrepancy between the two (explanation versus experience).

3.3.2.2 Getting through. This subtheme captures how participants endeavoured to cope with and manage the challenges they faced, and to regulate their emotional responses experienced during the neuropsychological assessment

process. Participants utilised a range of different coping strategies, including remaining task focused, switching off, trying to remain positive, thinking ahead and focusing on their goal of wanting answers. Some participants used a variety of coping strategies whereas others maintained the same response throughout. Many participants described using well-practiced coping strategies whereas for others, the neuropsychological assessment process created new challenges requiring them to adopt new ways of coping.

Participants had described how emotionally intense the neuropsychological assessment experience was for them (see section 3.3.2.1) and how for many this had threatened their sense of self. Coping strategies adopted seemed to be self-protective and aimed at alleviating their distress and/or minimising threats to their self-concept.

Many participants talked about trying to remain task-focused as a means getting through their experience. As Mick put it:

“I think when you’ve got that paper...you are just focusing on that...well with me it is anyway...not got anything else in my mind...just err...the questions and my answers...channeled everything else out...

(Mick, p. 8-9, lines 119-122)

There is a sense here that Mick channeled all his efforts into focusing on the tasks, tackling one thing at a time. For Mick, he maintained the same coping strategy throughout the neuropsychological assessment. The way Mick spoke about being focused seemed to highlight the dual purpose of his strategy: firstly enabling him to

distance himself from his emotions, and secondly providing him with a sense of control over an uncertain situation.

For Jean, being task-focused was one of several strategies she used and translated into working hard in order to try and demonstrate her strengths:

“I did try hard over the whole thing because what’s the point in not trying, if you know your...you know if you know it’s...erm...an assessment...and...try and show what you are capable of...yes” (Jean, p. 15, lines 242-245)

This excerpt highlights how Jean tackled the neuropsychological assessment in the same way she might approach any test, to work hard, hoping that perhaps this will demonstrate her capabilities. When talking to Jean, there was a sense that trying hard enabled her to feel as though she had done her best no matter what the outcome might be, therefore reassuring her in some way and also preserving her sense of self.

When things did not go to plan however and Jean felt unable to complete the task, she coped with this by wanting to move on in order to “progress” and find a task that she might be able to do:

“I just said to her “oh no, just forget...no, can we go on”, or something like that, “I can’t do it”, so I left it, and went...which I think is the right thing to do to progress, cos I might manage better on the next one” (Jean, p. 20, lines 332-336)

Here Jean describes managing her difficulties by wanting to move on to the next task. There is a sense that for Jean, focusing on positive aspects of her performance and not dwelling on tasks she found difficult is perhaps her way of protecting herself from experiencing failure or disappointment. Avoidance as a way of coping with negative experiences was interpreted as Jean trying to maintain her sense of self as being capable. Whilst for Jean, switching off from difficult situations and moving on was something she described herself as routinely doing in her life, for others this represented a completely new way of coping. As David explains:

“It was the first time I’d experienced having to switch off...not being able to do it, NO, no...not had that before” (David, p. 11, lines 186-188)

For David, this experience of not being able to do something appears to have taken him by surprise. David’s sense of self was strongly associated with his ability to *“overcome any challenges in life”* (p. 11, line 185), and his usual coping style was to work through and problem solve the situation. Being unable to adopt his usual coping strategy appears to have left David feeling overwhelmed and frustrated. With no obvious solution available to him, David attempts to resolve his distress by discontinuing the task. There is a sense here in how he uses the words “switching off” that he is trying to disconnect from his experience in both a physical and emotional way.

Other participants described trying to reduce their emotional distress by thinking ahead and focusing on pleasant things they had planned to do after the neuropsychological assessment. Terry's comments seem to capture this shared experience:

"kept thinking about after this is finished "I'm going to go down the shops and do so and so", I was thinking about other things" (Terry, p. 25, lines 404-406)

Terry had previously talked about feeling extremely worried about the outcome of his assessment, he has teenage children, and for him the thought of having dementia, was at times too distressing to even consider. The outcome of being assessed, as with all participants, had the potential to significantly impact on them and their family's lives. Earlier on in his interview, Terry had talked about feeling like he wanted give up during the neuropsychological assessment (*"I did feel at the time, just giving up"*, p. 24, line 381-382) but felt that it was important for him to continue. Here there is a sense that in thinking about doing something nice at the end of the neuropsychological assessment, this allowed Terry to disconnect from his emotions sufficiently enough to enable him to complete his neuropsychological assessment, thus achieving his goal.

Many other participants also adopted a goal directed approach in order to cope with the neuropsychological assessment. For Janet, focusing on her desire to find out if she had dementia enabled her to cope with her distress at being assessed:

“I...I...wanted to know whether I had...I had dementia or not (pause) so (pause) THAT I felt was the only way of erm of getting that answer, so I knew that I had to do it, and if you know, well, whatever I did was going to get the results, so mmmm...”grin and bear it...it was the results...that’s the important thing” (Janet, p. 10, lines 156-160)

Whilst the neuropsychological assessment was an intensely anxiety provoking experience for Janet, her need to know if she had dementia or not appeared to be the main motivating factor that enabled her to be accepting of the pain and persevere with completing the neuropsychological assessment.

3.3.2.3 Tell me how I’m doing: making assumptions. This subtheme captures how the nature in which the neuropsychological assessments were administered left participants with unanswered questions about how they were performing on the tests. In the absence of receiving feedback during the neuropsychological assessment, participants sought to resolve their uncertainty by attempting to appraise their own performance. Relying on their subjective appraisal resulted in all participants assuming they had performed poorly, meaning that some had misinterpreted their performance. Participants routinely used their self-appraisals to make predictions about their neuropsychological assessment outcome, with many participants fearing that they would be diagnosed with dementia, irrespective of their eventual outcome. Waiting for feedback prolonged participants’ anxiety for some, and for others maintained their uncertainty and compounded fears.

For many participants, the neuropsychological assessment process and way in which these tests were administered left them questioning how they were doing, and seemed to reinforce their sense of uncertainty about their abilities. Here Derek talks about being moved on from one test to another and the impact this had on him:

“they say “well the next one is this”...and I was [thinking]...”well how did I get on”...err...I mean “did I take twice as long as everybody else?” or “was I extremely quick?” (Derek, p.11, lines 176-180)

This excerpt seems to illustrate how, for Derek, the absence of receiving feedback in the moment left him with unresolved questions about how he was performing. It is interesting how his dialogue here is internal and how he does not direct his questions to the psychologist, which has been interpreted as Derek finding the neuropsychological assessment process disempowering. This sense of not knowing was significant to Derek and he goes on to emphasise just how confusing and frustrating it was not to receive any feedback:

“said “well now how much can you remember”, I had NO IDEA whether that was...good, bad or indifferent...my response to that, so I was given no clues” (Derek, p. 13, lines 225-228)

Here Derek’s frustration about not receiving feedback is evident in his emphasis of “NO IDEA”. Derek had previously talked about how he championed the notion of the “expert patient” and how it was important for him to have

knowledge and insight into what was happening to him. There is a sense here that perhaps Derek feels the psychologist is choosing to hold on to information about him, in the way he talks about not being given any clues. Janet described similar experiences to Derek:

“while you are actually doing these tasks “am I doing it right”, when they “STOP that”...you don’t know why they’ve stopped “is it the time...time’s up” or “are you doing...made such a mess of it you don’t need to do it anymore” cos you...you’ve proved a point really...erm...so there isn’t any positive feedback...well no feedback (laughs) during it erm well not really ...you just...DON’T KNOW...don’t know whether you’re doing right or not....” (Janet, p. 6-7, lines 94-101)

Janet’s need to try and understand how she is performing is evident here in her questioning whether she is doing ok. Again there is a sense that Janet was asking a question of the psychologist however this remained internalised rather than spoken, perhaps highlighting how restrictive/formalised the process felt for her. Janet had also previously spoken about how important the neuropsychological assessment was for her in determining whether or not she had dementia. Her struggle to make sense of her neuropsychological assessment experience is shown here in how she considers different possible explanations for why the tests suddenly stopped; those that relate to external factors (i.e., test rules) and those that relate to

internal factors (i.e., there is problem with her). Her strong desire for feedback is also evident and without this Janet remains confused and unsure about how she is performing. The researcher interpreted Janet's laughing as her attempting to lighten the mood, when actually it appeared during the interview that she had felt extremely frustrated and annoyed with not being given any feedback during the neuropsychological assessment.

Others described how they found themselves questioning how they were doing throughout the entire neuropsychological assessment process:

"I was more worried all the way going through, as I was answering the questions, when it went to the next question I was going back and thinking to myself "did I answer that right?" (Terry, p. 22, lines 350-352)

For Terry the lack of feedback seemed to compound his worry and anxiety about his performance, resulting him spending much of his time monitoring his performance in order to try and make sense of how he was doing.

The absence of feedback during the neuropsychological assessment had left many participants feeling confused and uncertain about their performance. Many described this uncertainty as distressing, and participants sought to resolve this 'threat' by actively trying to make sense of and appraise their own performance. For

some participants this meant monitoring the psychologist's actions in order to try and identify and interpret potential clues:

Terry comments seem to capture this shared experience:

"I thought, cos [psychologist] was there giving a little tick or cross and going through it and I thought, and I could see [psychologist] doing it and I thought "oh dear got that wrong, got that wrong"
(Terry, p. 22, lines 353-356)

Here Terry describes being acutely aware of how the psychologist was reacting or scoring each of his responses. Terry is clearly using this information to try and understand how he is performing and makes inferences based on his assumptions. His actions resulted in him assuming he had answered most questions incorrectly. There was a sense when talking to Terry that his need to know how he was doing, and lack of feedback, drove him to look for answers elsewhere. Interestingly enough, he later went on to explain that when he received his feedback he realised that he had been interpreting the psychologist's scoring incorrectly, highlighting the inaccuracy of his appraisals.

Others, such as Janet, used her own experience of the neuropsychological assessment to inform her appraisal of her performance:

"doing those tasks and not being able to err (pause) do some of the...you know running out of time you know...JUST CONFIRMED

that my memory is RUBBISH and you know that...I couldn't do it"

(Janet, p. 8, lines 127-130)

For Janet, her experience of the neuropsychological assessment seemed to reinforce her fears about her perceived failing memory ability. Here she uses cues from the assessment (i.e., time running out) to make assumptions about her performance, reaching the conclusion that she had performed badly. This is shown not only in her use of language to describe events but also in the way she emphasises the words "JUST CONFIRMED" and "RUBBISH", suggesting their saliency in her experience.

In the absence of receiving feedback during the neuropsychological assessment, participants not only made assumptions about their performance but also went on to question and make predictions about what their neuropsychological assessment outcome might be, leaving many feeling confused and worried. Here Zeena describes trying to make sense of her perceived inability:

"“how come I can't do it, no” so, like “may be I am, you know...there is something wrong with me...” , but I...I you know, I just didn't know”

(Zeena, p. 10, lines 171-173)

This excerpt seems to capture Zeena's surprise and worry at feeling unable to complete a certain test. Zeena had spoken at length of knowing her capabilities and priding herself in being able to tackle and conquer all manner of difficulties in

life. Perceiving herself as being unable to complete the task successfully appears to have left Zeena wondering and worrying about the reason for her difficulty. In the absence of receiving feedback she seems to draw on her own appraisal of the situation in order to try and make sense of the mismatch between her past and current self-view, resulting in her questioning if something is wrong with her. There is a sense of hesitancy here as Zeena reflects on her lack of objective knowledge to reach this conclusion, thus maintaining her confusion.

David shared similar experiences to Zeena:

“I did think “right that’s it I’m on my way out, err mentally” after I’d been to these assessments, you know I just couldn’t do them, some, it wasn’t like me, that’s what...well I thought “this might be REALLY bad”, and you don’t know, they don’t tell you right away, that’s well that’s frustrating” (David, p. 18, lines 301-306)

Here he describes his frustration at not being given feedback during the neuropsychological assessment and how his experience of being unable to complete the tasks lead him to think he was losing his intellect. David had previously talked about seeing himself as a capable person and feeling unable to complete the tests was a shock to him. Without objective external feedback he uses his experience of the neuropsychological assessment to inform his appraisal and prediction of the outcome (i.e., I can’t do this, therefore this might be really bad).

Other participants talked about how their experiences of their neuropsychological assessment lead them to assume they had dementia. As Janet put it:

“I definitely thought it would be dementia” (Janet, p. 11, line 165)

Janet’s experience of the neuropsychological assessment left her convinced that she would be told she had dementia, despite not actually knowing this. She went on to describe how her evidence for reaching this conclusion was based purely on her inability to complete certain tasks:

“I just err, you know...KNEW...I couldn’t do it so therefore one task proved to me that I had dementia” (Janet, p. 11, lines 169-171)

Without receiving external feedback, Janet was left with trying to make sense of her experiences through other means. It is interesting how her experience lead to her to believe she had a dementia, as her results were actually inconclusive.

Participants also described how waiting for feedback exacerbated their anxieties and maintained their uncertainty about themselves:

Eric’s comments seems to capture participants’ shared experience:

“you’ve got the review time, haven’t you...waiting for the results to be brought to you...that...that was the worst, you know...the waiting

“what this...what that...” I dunno really, you...so yeah that WAS FRAUGHT...cos...you are questioning everything... going back “it was bad”...but then...mmmm (pause)...” (Eric, p. 11, lines 182-186)

This illustrates how, for Eric, as with many participants, waiting and not knowing translated into more time to reflect on and think about their performance and possible outcome. In emphasising how fraught Eric felt demonstrates just how stressful waiting was for him.

Derek also described his feeling of turmoil:

“there was a mixture...of...a mixture of worrying and rationalising, worrying that it must be bad news, assuming it was and then trying to think... “was it really that bad, may be I did ok, you’re always hard on yourself” erm...and err...I just hoped (sighs) it wasn’t a bit of bad news really...” (Derek, p. 15-16, lines 261-266)

This illustrates how waiting and not knowing was intensely anxiety provoking for Derek and how he tried to manage his anxiety by remaining rational and considering the facts. Without this information to resolve his worries he attempted to remain hopeful in order to try and alleviate his distress.

For others, waiting for their results seemed to compound their fears:

“I just kept thinking well “I probably have got dementia and that’s probably what we’re going to hear when we come...go back” (Janet, p. 11, lines 175-177)

Janet describes how waiting left her thinking, and thinking resulted in her predicting what would happen, thus maintaining her fears.

3.3.3 Professional roles: different sides of the same coin

The third superordinate theme, “Professional roles: different sides of the same coin”, refers to the way in which psychologists interacted with participants during the neuropsychological assessment, and the impact this had upon them. What appeared significant to participants was the way in which the psychologist, who conducted their neuropsychological assessment, responded to them differently at different stages of the neuropsychological assessment process (e.g., clinical interview versus testing phase). Participants described a dichotomised approach. Participants experienced the clinical interview as person-centred and collaborative, resulting in them feeling involved and valued, whereas they described the testing phase as predominantly task-focused and didactic, with the psychologist’s approach experienced as more demanding/directive than collaborative. Consequently, many participants reported feeling disempowered and sidelined. The contrasting subthemes: “seeing the person” and “sidelining the person” will be explored in more detail below:

3.3.3.1 Seeing the person: being involved. This subtheme captures how participants experienced the psychologist as person-centred and collaborative during

the clinical interview, and considers the impact this had on them. Participants described the psychologist as welcoming, friendly and understanding, which seemed to dispel their initial worries and feelings of apprehension. This attentive and empathic approach appeared to create a trusting and safe space in which many participants felt able to openly discuss their difficulties and concerns without the fear of being judged. Participants felt genuinely listened to, and being treated like a normal person was an important experience for many, enabling them to feel involved and valued, and see themselves as greater than the sum of their difficulties. For some, their positive experience was tempered with feelings of anxiety and unease at the prospect of undergoing a neuropsychological assessment for possible dementia.

Participants had previously talked about feeling a sense of apprehension and uncertainty in the lead up to them having their neuropsychological assessment, with many concerned about what the neuropsychological assessment might be like and how they might be treated (see section 3.3.1.2). In contrast to their initial apprehension, many participants described feeling welcomed, relaxed and put at ease by the psychologist's approach, which seemed to foster a feeling of trust.

Here, Jean describes the impact the psychologist's approach had on her:

"it was all relaxed and friendly and laid-back" (Jean, p. 27, line 461)

For Jean, it appeared that the psychologist's friendly approach created an environment in which she felt relaxed and laid-back, perhaps dispelling her previous

fears about the neuropsychological assessment feeling intrusive and exposing (see section 3.3.1.2). It is interesting how Jean uses the word “friendly” to describe how the psychologist interacted with her, and the researcher wondered if this indicated that Jean experienced their relationship as collaborative and of equal standing. When talking to Jean, there appeared to be a sense of relief in her voice as though, perhaps, she had anticipated that the psychologist would respond to her in a formal and detached way rather than the “friendly” approach she encountered.

The psychologist’s “friendly” and collaborative approach seemed to foster a trusting relationship in which many participants felt safe to openly discuss their problems and concerns, without the fear of being judged:

*“I was a bit apprehensive at first, but oh (sounded surprised)
[psychologist] put me at ease straight away, as I’s said we were
having quite a chat, [psychologist]’s ever so nice, ever so
nice...chatting away and it all coming out (sighs)”* (Terry, p. 16-17,
lines 257-261)

Here, Terry describes how his initial apprehension soon disappeared and he felt relaxed and comfortable. As with Jean, Terry’s tone of voice seemed to indicate a sense of surprise and relief as though perhaps he had not expected to feel this way. His use of the word “chatting” seemed to indicate a sense of informality and reciprocation between himself and the psychologist, which appeared to facilitate open discussion.

Particularly poignant for participants, was how they felt the psychologist treated them like a “normal person” and really listened to what they had to say.

Terry’s comments seem to capture the participants’ shared experience:

“It’s the way [psychologist] spoke to you, [psychologist] spoke to you like you were a person, not as somebody who’s got something wrong with them” (Terry, p. 9, lines 127-129)

There appears to be a transformative quality about the psychologist’s interaction with Terry, as though in being spoken to as a person, Terry was able to see himself as a person, rather than feeling like someone who has “something wrong” with him. This seemed to be an important experience for Terry. He later talked about a previous encounter with a different clinician in which he felt his views were discounted and the emphasis was placed on identifying his difficulties. Terry described how this had left him feeling dismissed and unimportant, as though he was an object rather than a person *“I was just an object sat on a chair, that’s how I felt”* (Terry, p. 34, line 566). These past experiences appeared to be particularly stigmatising and dehumanising for Terry and the researcher wondered if this resulted in him seeing himself as defective in some way. The current interaction appeared to be a powerful and positive experience for Terry, enabling him to integrate his difficulties into a new perceived sense of self, resulting in him feeling re-humanised and valued.

The importance of being treated like anybody else also came through in Zeena's account:

“the lady I saw yeah, she was so nice, talking to me asking me things, I didn't feel like I forget things or things like that yeah, soo...it was easy for me I think when I came initially” (Zeena, p. 1, lines 6-9)

In the extract above, Zeena describes how the psychologist actively encouraged her involvement in their discussion in the way she spoke with Zeena and asked her questions. In maintaining a curious rather than assumptive approach, the psychologist appears to demonstrate to Zeena how valued her input is. This seemed like an important experience for Zeena to have. She had spoken passionately about her pride in helping others and feeling useful, and had disclosed her concerns about how others might view her now she was experiencing memory problems (see section 3.3.1). This seemed to highlight her fears about becoming useless and perhaps feeling stigmatised by others. The psychologist's approach here seems to have dispelled Zeena's fears by providing her with a different perspective in which to view herself as still useful. What is also interesting here, is how Zeena uses the word “initially” at the end of her sentence, which has been interpreted as her alluding to the fact that perhaps the latter stages of the neuropsychological assessment did not feel so comfortable and the psychologist's approach changed (see section 3.3.3.2 for further discussion).

Whilst most participants had described how the psychologist's approach enabled them to feel at ease, Janet's experiences seemed to highlight the tension she felt between experiencing the psychologist as nice and friendly yet feeling unable to really relax:

"She listened, you know, that bit was...took time with me...seeing how I was really, listening, relaxing...well as it...relaxing as it could be (laughs) didn't feel too bad to begin with so..." (Janet, p. 3, lines 34-36)

For Janet, taking time and being listened to, helped her feel relaxed to some degree, however what comes across in this excerpt is just how difficult she found it to escape from the anxiety she felt in being assessed for possible dementia. In this passage, her laughing was interpreted as her perhaps feeling awkward. The researcher wondered if it was difficult for her to talk about how anxious she felt given how attentive the psychologist was to how she was feeling. As with Zeena, there is also a sense here that Janet's experience changed across the duration of the neuropsychological assessment.

3.3.3.2 Sidelining the person: lost in the process. In contrast with the previous section, this subtheme captures how participants experienced the psychologist's approach during the testing phase as predominantly task-focused and didactic. Many highlighted a shift in the balance of power within their relationship, with the psychologist experienced as more controlling and secretive than

collaborative and open. Participants described feeling disempowered and lost in the process, which translated into some feeling unable to ask questions or openly view their concerns. Whilst some participants tried to rationalise why the psychologist changed their approach, many were left with unresolved feelings of frustration and anger.

Participants experienced a distinct change in the psychologist's approach towards them, from being collaborative and open during the clinical interview to being more controlling and closed during the testing phase. Janet's comments seem to capture the participants' shared experience:

“it was a bit like a driving test where the driving erm...tester isn't able to say anything to you during it...you know...no feedback no NOTHING just instructions of how to...you when to turn...and well it was a bit like that really” (Janet, p. 7-8, lines 113-117)

Here, Janet compares her experience in the neuropsychological assessment with her experiences of going through a driving test. What seems to come across in this excerpt is how, during the neuropsychological assessment, she saw the psychologist in a position of power, making demands and giving instructions, with her occupying a more passive role. Whilst she acknowledges how the psychologist is governed by the “test rules”, her frustration at not receiving any feedback from the psychologist is evident. There is a sense here that the power differential left Janet feeling constrained by the process and powerless.

Jean also described having a similar experience to Janet.

*“...this friend sort of...saying “don’t do it that way, do it this way”,
erm...(pause) not intentionally I have to say, because that’s THEM as
a person they’re a bit...(pause)...arrogant, erm...and they’re always
right, erm...and I find that...tricky...erm...I...(laughs)...I’d rather not do
it in front of them what I’m doing”* (Jean, p. 23-24, lines 393-399)

Here, she uses a recent incident with a friend to represent her experience of the psychologist. Jean describes how her “friend” is barking instructions and appears to be asserting her authority, which results in Jean feeling uncomfortable and exposed. The researcher interpreted this as Jean perhaps holding a conflicting view of the psychologist, as friendly on one hand but demanding and judging on the other. It is interesting that both Janet and Jean used an analogy to describe their experiences and the researcher wondered if they found it difficult to openly express negative views about the psychologist.

Feeling judged was a common experience for most participants:

*“they are judging in some ways, judging you...aren’t they, that’s the
point mmmm it’s a TEST (laughs)”* (Janet, p. 8, lines 130-132)

Whilst Janet states that ‘being judged’, is the point of the test, it is interesting to consider why she uses this word instead of perhaps “assessing”. The researcher wondered if her experience felt much more personal than being assessed, as though

she felt the psychologist was judging her as a person. This uncomfortable feeling came across in the interview and her laughing was interpreted as her trying to detract from how difficult this was for her.

Participants also described how they felt the psychologist changed from being open and sharing information, to withholding information and being closed, leaving many feeling frustrated and disempowered:

“they had a crib list...but that’s no help to the patient...because they won’t answer your questions...you can’t ask questions while you’re doing it...(sighs)” (Eric, p. 4, lines 56-58)

There is a sense that, in withholding information, Eric experienced the psychologist as withholding their support. The closed nature of their interaction appears to have translated into Eric feeling unable to ask questions as though he has become closed off himself. His sighs at the end of the passage seem to indicate a sense of resignation perhaps highlighting how powerless he felt.

For Derek it was as though the information being withheld represented a ‘clinical secret’:

“it was like a CLINICAL SECRET annnndddd...let me think about that...YES because if you le...if you let out the clinical secret then I don’t think that I can do the tests properly...” (Derek, p. 18, lines 307-310)

Derek had talked at length about his belief of the importance of being in the role of the “expert patient”, and how knowledge enabled him to feel in control of himself and the situation. This extract seems to highlight how he experienced the psychologist in a position of control/power, deciding what information he had. When speaking to Derek, his frustration and anger was evident. The researcher wondered if this left Derek feeling excluded and undermined as though he had been placed in a position of being powerless. There is also a sense of sarcasm in how Derek thinks through why this information has been withheld, as though perhaps as the patient he felt he was not trusted to know this information.

3.3.4 Finding out...

Integral to participants’ neuropsychological assessment experiences was finding out their results and attempting to move on. The fourth and final superordinate theme explores participants’ responses to receiving their neuropsychological assessment results, the impact it had on them, and the ways in which they attempted to cope and adjust to this moving forward. For participants, receiving their results was an immensely emotive experience. Participants’ responses were influenced by the outcome they received and the way in which they made sense of this. Participants used a range of different coping strategies to help them adjust to their outcome moving forward. Each of the subordinate themes “being told” and “trying to adjust and move on” are presented and explored in detail below.

3.3.4.1 Being told: mixed emotions, mixed responses. Being told the outcome of their neuropsychological assessment, marked a pivotal point in the

process for all participants, with the main driver being to understand their difficulties and find out whether or not they had a dementia. This subtheme explores participants' reactions to receiving their results and the impact this had on them and their sense of self. Participants' reactions and responses were influenced by the outcome they received and how they made sense of this. Participants' outcomes differed; some were given a diagnosis of dementia whilst others were told their difficulties were attributed to psychological factors, some results were inconclusive and one participant was told he did not have any impairment. Responses varied and included feelings of shock, disbelief, confusion, frustration, loss, validation and relief.

Participants (Terry and David) who were given a diagnosis of AD described slightly different reactions.

For Terry, thinking that he might have dementia, in no way prepared him for the shock of actually being told he had dementia:

“it’s like... you think it, cos you know you aren’t doing...aren’t doing things right...but well...but well...you DON’T WANT IT (pause), when you get it” (Terry, p. 31, lines 505-507)

Although his prediction was accurate and therefore in a way served to resolve his questions about himself, there is a sense here that Terry would have welcomed being incorrect. In emphasising not wanting “it”, the researcher

wondered if Terry felt there was no escaping from being seen as a person with dementia, perhaps highlighting how stigmatising he felt this diagnosis was.

David described feeling a sense of resignation in being given a diagnosis of dementia:

“I didn’t really expect a lot different from what I got, but I am concerned about how the family have gone, and how my brother is less than 4 years older than me” (David, p. 20, lines 341-344)

David has a significant family history of dementia, and there is a sense here that in confirming his fear about having dementia that David’s fears about his future are also confirmed.

Finding out their memory problems were associated with psychological factors rather than dementia was a huge sense of relief for some participants (Derek and Mick). Whilst Mick had described feeling emotionless throughout much of the neuropsychological assessment, his relief in finding out he did not have dementia was clearly evident in the interview:

“it was better...than I thought...I thought I’d done bad...you know...thought it’d be really bad...so I was relieved” (Mick, p. 12, lines 164-166)

Derek described similar feelings to Mick:

“the best bit was when she told me that I didn’t have a problem, so that was the best bit...so...I mean there might be reasons why I forget things but those reasons were identified” (Derek, p. 9, lines 147-150)

Here Derek emphasises just how important and meaningful it was for him to be told he did not have a dementia, shown in the way he repeats the words “best bits”. It is interesting how he relates not having dementia with not having a problem as though perhaps he perceives anything else as changeable and under his control. Not being given a diagnosis of dementia at this time, allows Derek to consider the results from his neuropsychological assessment in a much less threatening way and the explanation he is given allows him to make sense of his difficulties, thus resolving his internal uncertainty and angst.

For others (Janet and Zeena) their results were inconclusive warranting a further neuropsychological re-assessment. This uncertainty left them feeling confused and with unresolved questions about the reason for their difficulties. Here, Janet describes how she felt:

“I suppose the feedback was that there was NO ANSWER, well yeah really...it didn’t show one way or another.... (pause)tha...that’s difficult (pause)...I thought it would say...they would be telling me...us...that I had dementia...my memory is SO RUBBISH, but the...the tests were not picking that up as badly as...as I...as...I

THOUGHT (pause) (pause) so good in some ways errr...erm...yeah
confusing “is it dementia or not?” (Janet, p. 14, lines 227-233)

For Janet receiving no definitive answer was significant. She had spoken at length about her worries and expectation she would be told she had dementia (see section 3.3.2.2), and saw the neuropsychological assessment as her way of finding out. Whilst she appears relieved to some extent (i.e., no news is good news), she is ultimately left feeling confused and continues to wonder if she has dementia. Her perception of her memory difficulties appears far worse than her results suggested, and rather than being comforted by this, this leads her to question the sensitivity of the neuropsychological tests. This is demonstrated in the way she talks about the tests not “picking” up on her memory problems. There was also a sense that Janet felt disappointed and let down as she had pinned so much on the outcome of the neuropsychological assessment providing her with a definitive answer:

“it didn’t do what I wanted it to do really, no...gave me no real diagnosis about why my memory is so bad really” (Janet, p. 15, lines 238-240)

Her sense of despair comes across here and she is left unable to resolve concerns about herself and her inner turmoil is maintained.

Zeena shared similar feelings of confusion and uncertainty with Janet, however for her, not receiving an answer, resulted in her questioning her own perception of herself:

*“how can I be forgetting things am I making it up or what then,
but...I do REALLY genuinely forget things sometimes, you know, and
that’s why it worries me that...how come I’m forgetting”* (Zeena, p.
17, lines 293-295)

This extract seems to highlight Zeena’s internal conflict; on the one hand wondering if she is imagining her memory difficulties, given her neuropsychological test results, but on the other hand feeling sure that she does forget things. Being unable to reach a firm conclusion leaves her confused and worried.

For Eric being told that he did not have dementia was equally as confusing as this information appeared to conflict with his own perception of his difficulties and his experience of the neuropsychological assessment:

*“I really felt that...I’d done something wrong, you know, that it was
gonna be bad...BAD news, you know, but now they tell me there
isn’t...seems impossible really, but I guess...I guess it is...must be
right...”* (Eric, p. 5-6, lines 92-96)

Eric had found the neuropsychological assessment extremely stressful (see section 3.3.2.1) and his perception was that he had failed to complete any of the tests adequately well (*“I just couldn’t do the lot of it”*, p. 4, line 66), resulting in him

assuming it would be bad news. Eric appears mystified by his neuropsychological assessment results, which is demonstrated in the way he talks about it seeming impossible that he has not be diagnosed with dementia. Without being able to resolve this mismatch between his sense of self as having memory difficulties, and his results, he appears reluctant to accept his outcome, and his uncertainty remains.

3.3.4.2 Trying to adjust and move on. In making sense of their neuropsychological assessment experience, all participants described ways in which they attempted to adjust and cope with their neuropsychological assessment outcome. Participants had described how emotionally impactful receiving their results was for them and how for many this had threatened their prior sense of self (see section 3.3.4.1). The way in which participants coped was influenced by the outcome they were given and the way in which they made sense of this. Participants tried to adjust and cope in a range of different ways, including trying to compensate, trying to carry on as normal, accepting limitations, remaining hopeful, and reassuring themselves. Coping strategies adopted seemed to be self-protective or integrative and aimed at trying to achieve a positive sense of self.

Participants who received a diagnosis of AD described ways in which they attempted to compensate for their difficulties. Terry had talked about his shock at receiving his diagnosis and fear of losing control, and here he describes attempting to compensate for his future loss by organising and planning ahead:

“and on a Friday the last thing I do is get everything ready to make sure if anything happens to me, my wife picks ups folder and that’s it,

she knows where everything is, sorted, life insurance, pensions, everything else” (Terry, p. 27, lines 440-443)

In planning ahead now, it seems that Terry is perhaps preparing for an unknown and potentially threatening future by trying to ensure that his family are looked after, thus maintaining his role as husband and father and sense of himself as a competent, whole individual. Completing this task also appears to provide Terry with a sense of accomplishment and self-efficacy despite him feeling worried that his abilities have deteriorated (see section 3.3.1.1).

For David, using external aids enables him to compensate for his memory problems and allow him to maintain a sense of normality and control in his life now:

“I can live my life, I keep a day pad everything that I need to do today and then I’ll start sticking on things for tomorrow, I’ve got a laptop which I keep going erm, so I know what I’m doing” (David, p. 14, lines 223-235)

What came across from his account was how adopting his usual problem-solving strategy enabled him to maintain his sense of self as capable, which was in stark contrast to his experiences during the neuropsychological assessment testing phase when he felt unable to complete the tests (see section 3.3.2.2). Feeling and being perceived as capable and normal was important for David and he had spoken

about not wanting others to know he had been diagnosed with AD, perhaps suggesting how stigmatising the label of having dementia was for him.

For others, accepting their difficulties enabled them to integrate new knowledge gained from the neuropsychological assessment into a new view of their self. For Jean this translated into her accepting her difficulties within the context of her current capabilities and using this to remain optimistic about the future:

“I’ll consider myself quite fortunate if I continue to the end of my life...as I am NOW, I’d like to be brighter, I’d like to be a...as I used to be may be, erm...but...I feel at the moment I can...plod along quite merrily, quite happily erm, you know, ad infinitum” (Jean, p. 19-20, lines 323-327)

Although Jean acknowledges her deterioration and desire to want to return to her prior self, focusing on her current capabilities and what she can do has enabled her to accept herself. There is a sense that her acceptance only extends to how she views herself now, and despite her doubts, her hope that she remains the same is evident. The researcher wondered if this reflected her uncertainty about the meaning of being diagnosed with MCI.

For other participants (Mick and Derek), being told their problems were associated with psychological factors posed much less of a threat to their sense of self than being diagnosed with dementia, making it much easier for them to accept their difficulties. Here Mick describes his experience:

“now I don’t really think about it...it’s how I am...that’s me really...but a relief it’s ok...well not ok but you know...it could have been much worse” (Mick, p. 19, lines 270-272)

For Mick, finding out his difficulties were likely to be related to psychological factors was a huge sense of relief and seemed to immediately alleviate his distress. There is a sense that Mick felt that any other explanation was better than being told he had dementia, perhaps highlighting how stigmatising he viewed dementia as a diagnostic label. Mick’s acceptance of his difficulties is demonstrated here in how he refers to his “current self” in the present tense *“it’s how I am”*. This seems to indicate how Mick has integrated his understanding of his difficulties into a new and updated view of self.

For Derek feeling accepting of his problems enabled him to change his style of coping and become more accepting of himself. Rather than feeling frustrated and becoming angry with himself, he instead engaged in reassuring self-talk:

“now I know it’s based on anxiety and stress if I forget something then I just say to myself “well I’m a bit stressed out that’s obviously why I’ve forgotten it” (Derek, p. 28, lines 481-484)

In contrast with Derek and Mick, Eric’s attempts to reassure himself that he did not have dementia were less successful:

“and I have to keep reminding myself that, you know that there isn’t anything there, it’s not showing but err...I dunno know...I dunno, things just keep...you know my memory’s still bad, so...(sighs) (Eric, p. 21, lines 365-368)

Eric had previously spoken about his doubts over his neuropsychological assessment results and how they appeared to conflict with his self concept and experience of the neuropsychological assessment (see section 3.3.4.1). Here he describes trying to reassure himself *“that there isn’t anything”*, however continuing to have memory problems seems to reinforce his doubts, making it difficult for him to accept his results. His difficulty in accepting his results means his uncertainty about himself is maintained.

For participants who received inconclusive results (Janet and Zeena), coping was aimed as trying to adjust to the uncertainty of not knowing. In the absence of a definitive answer, both Janet and Zeena attempted to carry on as usual, thus demonstrating how they were still the same person. For Zeena this meant maintaining her usual “fighting” spirit:

“I’m trying to FIGHT everything, you know, that...to try and remember, you know, and I’m...I...I don’t want to be in that stage and things like that, you know, so I try to write everything down, you

know, I try not to be in that stage, you know, I'm a positive person, you know" (Zeena, p. 16, 269-273)

What comes across here is how Zeena is determined to tackle her problems head on and not be held back by her difficulties. There is also a sense that she is "fighting" the possibility of having dementia, in the way she talks about not wanting to "be in that stage". Fighting seems to serve a dual purpose in enabling Zeena to manage her difficulties as well as trying to maintain a view of herself as a person who does not have dementia.

Janet also talked about trying to carry on as normal, however for her the worry that she might have dementia seemed to interfere with her achieving this:

"I have to get on with it...trying to get on with it...trying to be normal (laughs) what that is (said quietly) trying to enjoy things, forget it"
(Janet, p. 16, lines 253-255)

What comes across here is how, in the absence of knowing whether or not she had dementia, Janet feels there is no other alternative than to try and accept things and get back to normal. However the uncertainty of not knowing continues to threaten Janet's sense of self, making it difficult for her to know what normal is. It is interesting how at the end of her sentence she says "forget it"; the researcher wondered if this, perhaps, represents just how impossible it feels for her to carry on as normal.

3.4 Personal Reflection on Process

March 2015

I've started reviewing the transcripts and what hit me is just how much I'm feeling pulled in viewing things from the perspective of being a clinician and keep thinking about how things might be changed in practice – so it's really struck me how I need to keep checking in with myself so that I'm bracketing this perspective off. I guess it's not surprising given that I've been learning how to be a clinician for the past few years! So I'm trying to slow down and step back and think about what the participants are trying to tell me about their experience and what was meaningful to them rather than zooming in on what sticks out to me.

April 2015

When I started looking at the results I felt liberated my being able to focus on each person's perspective, now I'm wondering how I bring it all together, without losing sight of the person. I'm new to this and I've been feeling a pressure to get it right! Had supervision today and it was really helpful to reflect on how I've been getting caught up in moving toward a more positivist perspective. Clearly there is no right way of representing what people have said and I realise that my interpretation is just one way of viewing the participants' experiences. Been thinking that perhaps this represents me wanting to do a good enough job in enabling participants to voice their opinion.

4.0 Discussion

4.1 Overview

This chapter will begin with an overview of the study findings, which will then be discussed in relation to relevant literature and theoretical understandings. The research methodology will be evaluated, taking into account issues of quality, and study limitations will also be explored. Clinical implications will be discussed and future research opportunities outlined. The chapter will finish with a final conclusion.

4.2 Summary of Study Findings

The current study explored participants' lived experience of neuropsychological assessment for possible dementia, with particular focus on how this has impacted on participants' sense of self, and how they endeavoured to adjust and cope with going through this process.

For the participants interviewed in this study, the meaning of undergoing a neuropsychological assessment, and the way they made sense of this, seemed to extend far beyond their experience of the actual neuropsychological assessment or testing sessions. Whilst the participants' experience of the neuropsychological assessment itself appeared to represent the mechanism by which they tried to make sense of the changes they had noticed in themselves, it formed part of a much wider conceptualisation of their experiences. Overall, participants described their neuropsychological assessment experience in terms of a very personal journey of discovery, characterised by uncertainty, turmoil and distress, and their attempts at

working hard to make sense of and ameliorate that uncertainty. Their experiences are conceptualised by four interrelated superordinate themes that emerged from the analysis of the interview data: (i) “things aren’t right: what’s wrong with me?”, relating to lived experience prior to actual neuropsychological assessment (ii) “testing by name, testing by nature”, (iii) “professional roles: different sides of the same coin”, relating specifically to their experience of the neuropsychological assessment, and (iv) “finding out: moving on”, relating to experience after the neuropsychological assessment. These themes and an interpretation of their associated meanings are summarized below.

4.2.1 “Things aren’t right what’s wrong with me?”

Neuropsychological assessment experiences were influenced by events that occurred prior to assessment. Participants spoke about becoming increasingly aware of, and trying to make sense of and manage, an altered self. Changes in self were related to finding certain everyday tasks more difficult and problematic to complete. Sabat (2001) described how part of our sense of self manifest in personal characteristics and attributes we associate with our identity (i.e., what make us, us). In the present study participants experiences appeared at odds with their expectations of themselves, generating a discrepancy between their “prior” and “current” view of self, thus threatening their self-identity. Participants spoke about how this internal discrepancy triggered a sense of uncertainty that left many questioning themselves and what was happening to them and wondering if their functioning was deteriorating. Participants’ awareness of their difficulties was distressing, and many spoke about how this negatively affected their confidence and

self-esteem. Other studies have reported similar experiences of uncertainty and distress as people become aware of their difficulties (Clare, 2003; Koppel & Dallos, 2007). Participants responded in different ways. Some initially tried to hide their difficulties from others, perhaps in some way trying to maintain continuity in their life (Atchley, 1989). Others sought to resolve this internal uncertainty by considering possible explanations, leaving many wondering if their mental state was deteriorating, and some expressed a concern that changes might be indicative of them having dementia. Theories of coping provide a helpful framework in which to understand these experiences and responses (Lazarus & Folkman, 1984; Park & Folkman, 2000). The recognition of difficulties was seen as representing a threat on a number of levels: a threat to self and a threat to others.

Seeking answers from professionals was seen as a practical way of resolving the uncertainty surrounding the changes participants were experiencing, in line with problem-focusing coping responses outlined by Lazarus and Folkman (1984). However rather than resolving distress, this response appeared to generate its own sense of threat: the notion of having to “fight” to be referred, in addition to the threat of what might be discovered (i.e., being diagnosed with dementia). Being referred to the memory clinic for assessment was problematic in itself. Repeated visits to the GP were not uncommon and there was a sense that health professionals were not taking their concerns seriously enough. The experience of participants in this study appeared different to those described elsewhere. Manthorpe et al. (2013) and Samsi et al. (2014) found initial contact with GPs was positive and helpful.

4.2.2 Testing by name testing by nature

Feeling uncertain about themselves appeared to provide a contextual backdrop in which subsequent assessment experiences were appraised. Overall the assessment Participants spoke of how they found the neuropsychological assessment for possible dementia a particularly intense and emotionally distressing time.

Emotional responses varied amongst participants, and appeared influenced by their perceived performance. Some participants portrayed their experience of the neuropsychological assessment as an emotional rollercoaster, characterised by a series of highs and lows. Enjoyment and confirmation of competence, associated with perceived success, were soon replaced by feelings of frustration and worry when participants were faced with tasks they found difficult or impossible to complete. Whereas for others being tested seemed to solely highlight their inabilities. Participants spoke of their disbelief in not being able to complete certain tasks they perceived as simple and straightforward. Finding different tests consistently difficult to complete, seemed to reinforce participants' prior fears that their cognitive functioning had deteriorated, resulting in them feeling a sense of loss, frustration, inadequacy, confusion and anxiety, thus compounding the threat to their sense of self as a capable individual. Others experienced the neuropsychological assessment process as isolating and described how they felt all alone and unable to seek support from others.

Despite receiving a detailed explanation of the neuropsychological assessment process, many participants described feeling ill prepared for the emotional reality of being tested. This perhaps highlights the discrepancy between

having a logical understanding of a set of procedures, and their subsequent emotional reaction to these.

Participants found the nature of the neuropsychological tests, and method of administration, strange and confusing, which appeared to exacerbate their distress and maintain their sense of uncertainty about their abilities. For many the tests appeared to feel devoid of real life abilities, leading some to feel as though they were “caught out”, whilst others questioned the usefulness of some tests. For many this sense of threat and uncertainty was experienced as them not feeling in control. This was also evident in Keady and Gilliard’s (2002) study where participants described feeling confused anxious, and uncertain of the purpose of the tests.

With the neuropsychological assessment viewed as the way for participants to make sense of the changes they had noticed in themselves, finding ways of “getting through”, in spite of their distress, emerged as important. Participants utilised a range of different coping strategies, including remaining task focused, ‘switching off’, trying to remain positive, thinking ahead and focusing on their goal of wanting answers. Coping strategies adopted seemed to be self-protective and aimed alleviating their distress and/or minimising threats to their self-concept. Some participants used a variety of coping strategies, whereas others maintained the same response throughout. Many participants described using well-practiced coping strategies whereas for others, the neuropsychological assessment process created new challenges requiring them to adopt new ways of coping.

Having to wait weeks for neuropsychological assessment feedback was a source of frustration for all participants. The lack of feedback provided during the

neuropsychological assessment appeared to compound participants' distress, leaving them with unanswered questions about their performance, thus maintaining their uncertainty and worry about their sense of loss of functioning. In the absence of receiving feedback during the neuropsychological assessment, participants actively sought to resolve their uncertainty by attempting to appraise their own performance. Without access to objective information about their performance, participants' appraisal of their functioning appeared informed by their subjective emotional experience. Participants had spoken about how they found the tests distressing and difficult, and this "bad" experience seemed to translate into them all assuming that they had performed "badly", and consequently predicting that their functioning had deteriorated. Participants routinely used their self-appraisals to make predictions about their neuropsychological assessment outcome, resulting in many fearing that they would be diagnosed with dementia. However, for some their subjective appraisal was inaccurate, resulting in them feeling increasingly confused and mistrusting of either the test results or of their ability to "understand" themselves (see section 4.2.4 for further discussion).

4.2.3 Professional roles: different sides of the same coin

The social context created by the psychologist during the neuropsychological assessment, greatly impacted on how participants perceived, experienced and responded during their assessment. Both positive and negative experiences were described. Of particular interest in the present study was how participants experienced the psychologist as occupying two opposing roles: person-centred and

collaborative during the clinical interview, and task-focused and didactic during the testing phase.

These opposing approaches seemed to generate opposing experiences, with participant responses mirroring that of the psychologist. The warm, collaborative approach (clinical interview), engendered a sense of trust, enabling participants to feel valued and involved, and openly discuss their difficulties without feeling judged. In contrast, the didactic and task-focused approach adopted during the testing phase was experienced as controlling and closed, creating an environment in which participants felt closed off and unable to voice their concerns. Different approaches were also associated with a change in the balance of power within the psychologist-client relationship. A collaborative stance engendered a sense of shared responsibility and power, whereas a directive approach was experienced as more controlling, with the psychologist seen as the holder of power.

In particular, it seemed that the changing nature of the psychologist's approach was especially unsettling, generating an overall sense of confusion, frustration and mistrust. Whereas initial interactions with the psychologist appeared to dispel pre-existing fears about the assessment process, the approach adopted during the testing phase only worked to reignite such anxieties.

In reality, it is the nature of the neuropsychological assessment process that influenced the psychologist's approach, as these need to be administered in a standardised way, to ensure test validity. What is interesting in the present study is that whilst participants tried to rationalise the reason why the psychologist was more directive (i.e., noting the need to administer tests in a certain way), the

unpleasantness of their experience appeared to translate into them seeing the psychologist as responsible for their distress.

Other studies have explored experiences of professional relationships within the context of dementia assessment (Cahill et al., 2008; Manthorpe et al., 2013; Samsi et al., 2014; Willis et al., 2009). The majority of these studies however have focused on relationship experiences at a broader level, labeling these as either positive or negative. Cahill et al., (2008) reported that in general, participants portrayed relationships with professionals in a positive light. Feelings of confusion and anxiety were noted, however these were not specifically related to participants' interactions with professionals. Willig et al., (2009) found a mixed reaction to professional involvement, with some participants feeling reassured by the clinician's approach and others experiencing staff as insensitive to their needs. Other studies related daunting and disempowering experiences with the assessment process, not commenting on the impact of the professional's approach within this, instead noting that professionals were viewed in a positive light overall (Manthorpe et al., 2013; Samsi et al., 2014). Whilst findings from the present study are consistent with previous research to some degree (i.e., suggesting that interactions with professional can influence assessment experience, and noting positive and negative experiences), the present study offers a new perspective on the role professionals play in shaping assessment experience.

The quality of the therapist-client relationship has long been noted as an essential foundation of effective therapy (Westbrook, Kennerley, & Kirk, 2010). Evidence relates the nature of this relationship to therapeutic outcome (Orlinsky,

Grawe, & Parks, 1994), with positive therapeutic alliance necessary for a good outcome (Wright & David, 1994). In relation to findings from the present study, this poses the question of how psychologists might foster a positive alliance, balancing the needs of the client with the requirement of administering neuropsychological assessments in a standardised way.

4.2.4 Finding out: moving on

Receiving the outcome of their assessment represented particularly pivotal point in participants' neuropsychological assessment experience. Participants' responses seemed influenced by the outcome they received and the way in which they made sense of this. Unique to this study was that fact that assessment outcomes differed. Receiving a diagnosis of dementia was associated with feelings of shock, resignation, and uncertainty about what the future might hold, consistent with previous research into dementia diagnosis experience (Aggarwal et al., 2003; Aminzadeh et al., 2007; Gillies, 2000; Holst & Hallberg, 2003; Husband, 1999; MacQuarrie, 2005; Pratt & Wilkinson, 2001, 2003; Robinson et al., 2005). Those told their difficulties were associated with psychological factors as opposed to dementia, experienced a huge sense of relief. The researcher is not aware of any studies that have explored the effects of receiving an alternative diagnosis to dementia. Relief associated with learning that problems could be attributed to psychological factors can be understood within the framework of illness representations theory (Leventhal, Nerenz, & Steele, 1984). This model proposes that the way people appraise and respond to a health threat is influenced by their health beliefs and information derived from symptoms and illness stereotypes. This

suggests that participants perceived psychological problems as much less threatening than the prospect of having dementia.

Expectations were that the assessment outcome would provide participants with a definitive explanation of the reason for their experienced difficulties. Inconclusive results left participants with unresolved questions, thus maintaining their uncertainty and confusion. For one participant, being told his results indicated no impairment was incongruent with his own sense of failure (*"I just couldn't do the lot of it"*, Eric, p.4, line 66), and as such, instead of being reassured, his outcome appeared to exacerbate his confusion and uncertainty. Research within the field of chronic illness is consistent with this idea that uncertainty has considerable impact on a person's ability to make sense of their situation and to incorporate changes noticed into a redefined sense of self (Charmaz, 2000). For example, if people are unable to attach meaning to their experience of "illness", this maintains a sense of uncertainty and vulnerability, leading to increased distress.

The neuropsychological assessment outcome also influenced the way in which participants attempted to adjust and move on in their lives. Coping strategies adopted seemed aimed at trying to achieve a positive sense of self and alleviate their distress. Those who received a diagnosis of dementia, spoke of adopting compensating strategies aimed at directly managing problems experienced, such as planning ahead and using external aids, which appeared to enable them to maintain their sense of self as capable and in control. These findings show support to Lazarus and Folkman's (1984) model of stress and coping, which suggests that coping responses are influenced by an individuals' appraisal of the stressor and their ability

to cope. A number of studies have reported similar findings suggesting that people with dementia use a range of different strategies to manage the effects of dementia, including problem-focused strategies, such as using memory aids, and focusing on what can be achieved (Clare, 2002; Gillies, 2000, 2001; Lee, Roen, & Thornton, 2014; Menne, Kinney, & Morhardt, 2002; Ostwald, Duggleby, & Hepburn, 2002; Pearce, Clare, & Pistrang, 2002; Phinney, 1998; Preston, Marshall, & Bucks, 2007).

Finding out their problems were likely underpinned by psychological factors, appeared particularly reassuring for participants, resulting in them being more accepting of their difficulties and less self-critical. Perhaps highlighting how they were more easily able to integrate this new information into a changed sense of self.

For those who received inconclusive results warranting further investigation, moving on appeared by nature problematic, and they described a sense of being suspended in uncertainty. Coping by “carrying on as normal”, seemed aimed at trying to hold on to their prior self-concept, as a person who does not have dementia, consistent with Atchley’s (1989) theory of coping, which asserts that people attempt to manage the stress of uncertainty by maintaining continuity in their lives.

However maintaining continuity in the face of uncertainty is not always possible. For one participant, the uncertainty of not knowing, seemed to translate into her questioning what “normal” was, resulting in her feeling unsure how to react, thus maintaining her distress.

4.3 Methodological Considerations

4.3.1 Demonstrating quality

The quality and value of research is judged by how rigorously methods are conducted and whether findings are trustworthy and meaningful (Smith & Osborn, 2008). In qualitative research, aims are to develop an in-depth phenomenological understanding of individual experiences from the perspective of the person experiencing it. Therefore, traditional ‘nomothetic’ methods used for assessing validity and reliability in quantitative research, are considered too simplistic and rigid to effectively evaluate qualitative research (Barker, Pistrang, & Elliott, 2002). Instead, Smith et al. (2009) suggested that guidelines developed by Elliot et al. (1999) and Yardley (2000, 2008) provide more helpful and holistic criteria, which can applied to any qualitative research study, irrespective of the theoretical orientation, and recommend either of these guidelines, for evaluating the quality of IPA studies. The way in which the current study fulfills these criteria is discussed in detail below:

4.3.1.1 Sensitivity to context. Sensitivity to context can be shown in a variety of ways: sensitivity to existing theoretical and empirical literature; sensitivity to participants’ perspectives, consideration of ethical issues, and sensitivity to data collected (Yardley, 2000). This study has demonstrated these qualities by providing a detailed review of theoretical and empirical literature in the introduction section. This allowed the researcher to identify gaps in current research and develop a set of research questions aimed at addressing this. Great care was also taken in designing the study, with emphasis placed on encouraging participants to express their views

freely (sensitivity to participants' perspectives). Issues such as power imbalance, and researcher's influence on the interview and analysis process were also considered. These were addressed by using open-ended questions and the researcher adopting a curious and active listening role. The researcher also considered how participants' cognitive functioning might impact on the interview process and made adjustments accordingly (e.g., using additional prompts, allowing sufficient time for the participant to respond). Consideration was also given to ethical issues throughout all stages of the study (see section 2.3 on ethical considerations, for further discussion). A detailed record of the data analysis process (see Appendices J-L) was generated and excerpts from participant interviews used to support interpretations being made, demonstrating sensitivity to data.

4.3.1.2 Commitment and rigour. Commitment encompasses in-depth engagement with the topic, development of methodological skills and competence, and immersion in the data (Yardley, 2000). The researcher demonstrated this quality in a number of ways. Firstly, as a novice qualitative researcher, developing an in-depth learning and understanding of IPA principles and learning core skills required to conduct this methodology effectively were key. In addition to reading about IPA and research papers that had adopted this methodology, the researcher also attended a two-day IPA workshop. The workshop provided teaching on the theoretical foundations and principles of IPA, and the process of conducting IPA, as well as practical exercises covering different aspects of the research process (e.g., developing an interview schedule, practicing interview techniques and completing a data analysis exercise).

The researcher also sought regular supervision from the clinical and academic supervisor in order to reflect on the research process and seek guidance where necessary. Transcribing all interviews personally and reading and re-reading transcripts allowed the researcher to become immersed in the interview data.

Rigour can be demonstrated through the choice of data collection and analysis, and the procedures used to conduct this thoroughly (Smith et al., 2009). In this study, semi-structured interviews were used allowing the participant to freely express their views, resulting in the capture of rich subjective data. The interview schedule was used flexibly as a guide, enabling the researcher to pay attention to the participant's cues and probe further, demonstrating commitment to the individual participant. Both individual and cross case analysis was used allowing the researcher to provide a balance of idiographic and nomothetic representation.

In this study, independent scrutiny was used as a way of enhancing trustworthiness of the analysis and to aid researcher reflexivity. The clinical supervisor reviewed the researcher's coding of several transcripts. The clinical supervisor and researcher then discussed the rationale for interpretations reached and reflected on how the researcher had reached conclusions made. The supervisors also reviewed drafts of the results in order to check the validity of the researcher's interpretations against verbatim quotes from participants' accounts.

4.3.1.3 Transparency and coherence. Transparency can be demonstrated through detailed and accurate disclosure of the research process (Yardley, 2000). The researcher attempted to ensure transparency by describing each stage of the research process in detail in Chapter 2 (e.g., participant selection and recruitment,

development of the interview schedule and pilot, process of analysis). In addition to this, an audit trail was generated, to show the stages of analysis, and demonstrate how the researcher's conclusions were reached. Examples of documents (e.g., annotated transcript, tables of themes and corresponding extracts, master theme table) are included in the appendices (see Appendix J-L) to evidence the analytic process.

Coherence refers to how well the method reflects the underlying principles of the approach used, and how well different parts of the research process link together (Yardley, 2000). To ensure research coherence, the methodological approach chosen in this study was aligned with the study aims of exploring individual experiences neuropsychological assessment for possible dementia, and the researcher's epistemological position of critical realism. The researcher also completed several drafts to ensure that arguments and processes coherently linked together.

4.3.1.4 Impact and importance. Yardley (2000) suggested the ultimate measure of research quality is the potential to have real impact: theoretically, practically or socio-culturally. In designing this study, the researcher hoped that findings might be useful in a number of ways. Firstly, increasing current knowledge about experiences of neuropsychological assessment for possible dementia, and exploring the impact this has on an individual's self-concept and coping, which is currently inadequately understood. Secondly, that recommendations may be developed from the findings of this research that enable the assessment process to be further refined in order to better meet the needs of patients. Most importantly, the

researcher hoped that in participating in this study and sharing their experiences, that participants' would feel valued as people.

4.3.1.5 Owning one's perspective. It is acknowledged that in qualitative research, the nature of methodological inquiry means that the researcher is intrinsically involved in every stage of the study process, from design through to data analysis. Elliott et al. (1999) discussed the importance of the researcher acknowledging and reflecting on their own subjectivity, by highlighting their pre-conceptions, values and interests, and considering the impact these may have on the research process and interpretations made. The researcher demonstrated reflexivity in a number of ways: providing a personal statement, explicitly outlining subjective beliefs, assumptions and experiences (see section 2.7.1) using a reflexive diary to identify personal reflections, thoughts and views; and through reflecting on research practice during research supervision. This allowed the researcher to identify how their own assumptions and beliefs may have influenced the interview process, data produced, and analytic process, and therefore "bracket off" such pre-conceptions. The researcher also included excerpts from the reflexive diary throughout the report, to aid transparency.

4.3.2 Limitations

It is important to consider methodological limitations when interpreting research findings. A number of study limitations were identified, and are discussed in detail in the next section. Suggestions for future research, identified as a result of limitations of this study, will be further explored in section 4.7.

4.3.2.1 Neuropsychological assessment. Participants recruited to this study were those that underwent a detailed neuropsychological assessment for possible dementia. As already discussed there are a number of different dementia assessment pathways (see section 1.5.3) and only a small proportion of people assessed for dementia will undergo a full neuropsychological assessment. Typically people who undergo a full neuropsychological assessment are those for whom initial cognitive screening results proved inconclusive, where estimated premorbid IQ may be very high or low, and/or where clinical symptom severity is very mild (Collerton & Domone, 2014). Therefore it is possible that the participants' experiences in this study may not be typical of all people who undergo a dementia assessment. However whilst this could be considered a limitation, this study sought to explore in-depth experiences of one particular aspect of the dementia assessment pathway, thus providing a rich and informative insight into "lived" experience of neuropsychological assessment in an area that is currently under researched. It is also hoped that in providing an insight into one aspect of dementia assessment experience, this will promote further research into exploring assessment perspectives of other groups.

4.3.2.2 Participants. Whilst all those recruited had undergone a neuropsychological assessment for possible dementia, outcomes from assessment varied, and only two people were diagnosed with a dementia. This meant that post-assessment sample characteristics were relatively heterogeneous, which may be considered a limitation, as multiple outcomes could have influenced assessment experience. When designing the study the researcher considered various options for

participant eligibility (e.g., whether to only recruit participants who had been diagnosed with dementia, or to include all those who had been assessed for possible dementia). IPA guidelines suggest that degree of homogeneity should be determined by the research question, and thus likely to be informed by the extent of existing literature in the area of study (Hefferon & Gil-Rodriguez, 2011; Smith et al., 2009). For example, where little or no existing literature exists, sample boundaries are likely to be broader, with a view of future research exploring sub-groups within this. As very few studies had explored experiences of dementia assessment, the researcher chose to recruit participants who had completed a neuropsychological assessment for possible dementia, irrespective of outcome. What was interesting in this study was how despite multiple outcomes, all participants, irrespective of their eventual outcome, appeared to begin their journey with similar perceptions held in mind (i.e., that they might have dementia). All participants also shared similar experiences of the neuropsychological assessment.

Although eligibility criteria were selected to be as inclusive as possible, only recruiting participants over the age of 60 years old and with mild impairment (MMSE score of 18 or above out of 30), may have affected the sample, by potentially excluding some people who had been assessed and might have been interested in participating in the study. However inclusion criteria in this study were inline with those adopted in similar studies that explored dementia experience.

It is also possible that whilst the researcher made every effort to include sufficient information about the study, enabling people to make an informed choice

about participating, that the information was too detailed possibly deterring some people with dementia from taking part.

Furthermore, although a high proportion of people contacted about the study subsequently chose to participate, those who did not may hold different views about their neuropsychological assessment experience, which this study was not able to capture.

Moreover, all participants interviewed spoke about becoming aware of changes in their cognitive functioning and initiated the assessment themselves, via their GP. Participants who were perhaps less aware of their difficulties or whom were encouraged to seek help by the families may well have reported different neuropsychological assessment experiences.

4.3.2.3 Recruitment. Given that all participants' were recruited from the same memory clinic, it may be their experiences were influenced in part by processes and procedures specific to that service, and therefore may not be reflective of experiences across other dementia assessment services. However when selecting the recruitment site the researcher reviewed the content of the neuropsychological assessment process used, which was consistent with NICE (2006) guidelines for dementia assessment. Whilst this study does not purport to overstate claims in terms of generalisability to a wider population, there was no suggestion that the practices adopted at this site differed from those used in other memory clinics. Furthermore, in selecting one site, the researcher was able to ensure to some extent that participant's experiences of the same "shared event" were explored, which is in keeping with IPA principles (Smith & Osborn, 2003).

4.3.2.4 Interview location. It is possible that being interviewed in the memory clinic they were assessed in may have influenced participants' disclosure about their neuropsychological assessment experience, as this was not considered a neutral environment. The researcher had taken steps to offer participants a choice of venue (i.e., clinic or their home) and where participants chose to be interviewed in the memory clinic the researcher ensured that a different clinic room was used. The researcher also took steps to make the participants feel as comfortable as possible by ensuring that the interaction between researcher and participants was different to a clinical interview, and also by highlighting that the researcher was not employed within the service. On reflection there did not appear to be any obvious differences in what had been disclosed between those interviewed in their home and those interviewed in the memory clinic.

4.3.2.5 Analysis. In IPA subjective experiences are analysed at both an idiographic and nomothetic level. In the present study although each transcript was analysed at an individual level before group comparisons were made, the researcher was aware of holding in mind themes that emerged from previous cases. It is possible that this could have influenced the idiographic focus of the analysis. To ensure that each transcript was recognised in its own right, the researcher checked that each theme identified was directly representative of that participant's words.

4.3.2.6 Researcher's position. It is also important to consider how the researcher's position, in relation to the research topic, may have affected data collection and interpretation of results. Having a particular interest in neuropsychological assessment and training as a clinical psychologist may have

influenced how the researcher responded to participants during the interview (i.e., following certain lines of enquiry during the interview) and the identification of certain themes within the interview data. Whilst accepting that any qualitative research is, by nature subjective, the researcher adopted a reflective stance throughout, in order to consider the impact of subjective thoughts and beliefs on actions and attempted to “bracket off” pre-conceptions as far as possible. For example, as highlighted in researcher’s reflective comment in section 3.4, the researcher was aware of being drawn into “seeing” the data through the eyes of being a clinician and reflected on this in supervision. Interview recordings were also reviewed to identify if the researcher was focusing on particular topics of discussion more than others.

The researcher was also mindful how her characteristics might influence how the participants engaged with the interview process and the information they chose to disclose. The researcher aimed to remain as neutral as possible and introduced herself as a researcher rather than a clinician.

4.4 Clinical Implications and Recommendations

A number of clinical implications have arisen from this research. There appears to be a mismatch between participants’ logical understanding of the neuropsychological assessment and their emotional experience and reaction. What was interesting here, was how despite the psychologist fully explaining the neuropsychological assessment process, and discussing the range of different possible assessment outcomes, many participants described feeling unprepared for

the reality of their emotional experience. This raises questions about how clinicians might address this and try to prepare people more thoroughly. Participants are unlikely to have been faced with completing “tests” for many years, and the potential consequence of “failing” (i.e., receiving a diagnosis of dementia) is likely to make these tests all the more meaningful and threatening. At the clinical interview stage it may be helpful for clinicians to discuss how different people have experienced being assessed. For example discussing how alien and emotionally intense being assessed can feel for many people, and how it can evoke a range of feelings and responses. In discussing different reactions beforehand this may help to normalise any subsequent emotional reactions the person experiences. It would also provide an opportunity for the clinician and person being assessed to collaboratively identify ways to help manage their emotions and experiences, should this arise. In this study, some participants had spoken about not feeling able to disclose their distress or ask for support from the therapist, due to the “closed” nature of the neuropsychological assessment, testing phase. Openly discussing, and hence normalising emotional reactions prior to neuropsychological assessment, may enable participants to feel more comfortable seeking support during and after the neuropsychological assessment, testing phase.

Another key issue that arose from this research was how participants described the psychologist taking on different roles, during different stages of the neuropsychological assessment process. Participants spoke about a discrepancy between the clinical interview, in which they described the psychologist as warm, person-centred and collaborative, and the testing phase, which was experienced as

predominantly process-focused and didactic. Whilst participants were aware that the neuropsychological tests needed to be administered in a standardised way, their experience of the psychologist occupying “opposing” roles appeared confusing and frustrating to some. Furthermore, it was also evident that not receiving feedback on test performance during the neuropsychological assessment increased participant’s anxieties and uncertainty about their performance. Again it may be helpful to explore these issues during the clinical interview and discuss how different stages of the process are likely to be experienced in different ways, and identify strategies to help manage this. Overall this highlights the complexity of the neuropsychological assessment process and raises the question about how clinicians’ might balance the need to administer neuropsychological assessments in a standardised way, whilst at the same time maintaining a warm, empathic approach, and taking into account individual needs.

Given that undergoing a full neuropsychological assessment is a lengthy, intensely emotional experience, fraught with uncertainty, it is important that clinician’s ensure people are not unnecessarily assessed. In the current study the majority of people did not receive a diagnosis of dementia. Whilst it may have been appropriate to assess all of these people, this does raise the question about how services decide who undergoes a full neuropsychological assessment. Current published memory clinic audit data (Hodge & Hailey, 2013), does not report prevalence of different outcomes following neuropsychological assessment. It may be helpful for clinicians to review this information within their service, and consider whether current procedures and processes adopted, best meet the needs of service

users. Asking questions about whether people are being unnecessarily assessed, or if there are other ways of reaching a satisfactory conclusion without the person needing to undergo a full neuropsychological assessment, may be beneficial to both the service user and also allow more efficient use of clinic resources.

Those who received inconclusive results seemed unable to resolve their uncertainty about themselves leaving many feeling disappointed and frustrated. Whilst participants were made aware that results might not be conclusive, it may be helpful to spend time during the clinical interview reflecting on participant's expectations about the neuropsychological assessment and considering how they might feel if they did not receive a definitive outcome. Receiving inconclusive results also raises questions about how people are supported during this time of uncertainty whilst they wait for their re-assessment. It may be helpful for service users to be followed up during this time to determine how they are coping, or provide them contact details should they wish to discuss concerns further.

4.5 Future Research

This research focused on exploring experiences of participants who underwent an in-depth neuropsychological assessment for possible dementia within a specialist memory clinic setting. However as already indicated only a small proportion of people assessed for possible dementia will undergo this detailed assessment. It would be interesting to conduct further research into experiences of dementia assessment for other groups of people. For example those who were assessed in primary care, or those who experienced a shorter screening assessment in a memory clinic setting or community setting, to consider whether experiences are

similar or whether different types of assessments impact on people in different ways. This might also be helpful for services in considering how they might adapt their approach to meet needs of people undergoing different assessments.

As already highlighted, all participants interviewed, had an awareness of their changing sense of self, which prompted them to seek further investigation of their perceived cognitive difficulties, via their GP. Future research could also explore experiences of others who were perhaps less aware of changes in themselves and for whom family members had prompted their assessment. It would be interesting to see how a lack of awareness might impact on the meaning they attribute to being assessed, and how this impacts on their sense of self and overall assessment experience.

The current study sought to explore participant's own experiences of neuropsychological assessment for possible dementia to enable their voices to be heard. Many participants spoke about how isolating the neuropsychological assessment experience was and how they were unable to use usual coping strategies of seeking support from others. This study did not explore how participants sought support outside of the neuropsychological assessment process. It may be interesting to extend this study further by exploring dementia assessment experiences from the perspective of the individual's supporter/family member. In understanding how the wider family experiences, and makes sense of going through the assessment process, may help inform systemic interventions, thus providing further support to the individual and their family. Another issue that would be interesting to consider is how it is decided who should undergo a full neuropsychological assessment, and

what underpins this clinical decision-making process. In the current study, many people who completed a full neuropsychological assessment did not receive a diagnosis of dementia, for various reasons already outlined. This may highlight the complexity and uncertainty around making a diagnosis of dementia. This uncertainty coupled with the potentially life-changing impact of receiving a diagnosis of dementia may well influence clinical decision-making (i.e., completing more assessments in order to be as certain as possible). Future research could investigate mechanisms that inform this decision-making process, which may be helpful in reviewing and refining current practices to make them more person-centred and less lengthy.

4.6 Final Conclusions

This study aimed to explore participants lived experience of undergoing a neuropsychological assessment for possible dementia, with particular focus on how this impacted on their sense of self, and how they endeavoured to adjust and cope. The use of IPA enabled in-depth exploration of idiosyncratic experiences, allowing the voices of each participant to be heard and valued. Four interrelated themes emerged from the analysis depicting participant's assessment experience in terms of a journey characterised by uncertainty, questioning self and their attempts to try and make sense of and manage that uncertainty. Themes that emerged were: "things aren't right: what's wrong with me?", "testing by name, testing by nature", "professional roles: different sides of the same coin", and "finding out: moving on".

References

- Age UK. (2014). *Later life in the United Kingdom*. London: Age UK.
- Aggarwal, N., Vass, A., Minardi, H. A., Ward, R., Garfield, C., & Cybyk, B. (2003). People with dementia and their relatives: Personal experiences of Alzheimer's and of the provision of care. *Journal of Psychiatric and Mental Health Nursing*, 10, 187-197. doi: 10.1046/j.1365-2850.2003.00550.x
- Agronin, M. E. (2014). *Alzheimer's Disease and other dementias* (3rd ed.). London: Routledge.
- Alzheimer's Disease International. (2009). *World Alzheimer's report*. London: Alzheimer's Disease International.
- Alzheimer's Society. (2007). *Dementia UK: The full report*. London: Alzheimer's Society.
- Alzheimer's Society. (2013a). *The dementia guide: Living well after diagnosis*. London: Alzheimer's Society.
- Alzheimer's Society. (2013b). *What is dementia with Lewy bodies* (Factsheet No. 403). London: Alzheimer's Society.
- Alzheimer's Society. (2014a). *Dementia UK: update* (2nd. Ed.). London: Alzheimer's Society.
- Alzheimer's Society. (2014b). *What is Alzheimer's disease* (Factsheet No. 401). London: Alzheimer's Society.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders: DSM-IV-TR* (4th ed. text revision). Washington, DC: American Psychiatric Association.

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-V* (5th ed.). Arlington, VA: American Psychiatric Association.
- Aminzadeh, F. Byszewski, A., Molnar, F. J. & Eisner, M. (2007). Emotional impact of dementia diagnosis: Exploring persons with dementia and caregivers' perspectives. *Aging and Mental Health*, 11, 281-290. doi: 10.1080/13607860600963695
- Atchley, R. C. (1989). A continuity theory of normal aging. *The Gerontologist*, 29, 183-190. doi: 10.1093/geront/29.2.183
- Barker, C., Pistrang, N., & Elliot, R. (2002). *Research methods in clinical psychology: An introduction for students and practitioners* (2nd ed.). Chichester: Wiley & Son.
- Barnes, D. E., & Yaffe, K. (2011). The projected effect of risk factor reduction on Alzheimer's disease prevalence. *The Lancet*, July 19, 1-10. doi:10.1016/S1474-4422(11)70072-2
- Beard, R. L. (2004). In their voices: Identity preservation and experiences of Alzheimer's disease. *Journal of Aging Studies*, 18, 415-428. doi: 10.1016/j.jaging.2004.05.005
- Beard, R. L., & Estes, C. L. (2002). Medicalization of aging. In D. J. Ekerdt (Ed.), *Macmillan encyclopedia of aging* (pp.883-886). London: Macmillan Publishing.
- Beard, R. L., Knauss, J., & Moyer, D. (2009). Managing disability and enjoying life: How we reframe dementia through personal narratives. *Journal of Aging*

- Studies*, 23, 227-235. doi: 10.1016/j.jaging.2008.01.002
- Bender, M. P., & Cheston, R. (1997). Inhabitants of a lost kingdom: A model of subjective experiences of dementia. *Ageing and Society*, 17, 513-532.
Retrieved from http://journals.cambridge.org/abstract_S0144686X90776570
- Beuscher, L., & Grando, V. T (2009). Challenges in conducting research with persons with dementia. *Research in Gerontological Nursing*, 2(1), 6-11. doi: 10.3928/19404921-20090101-04
- British Psychological Society. (2009). *Code of ethics and conduct*. Leicester: British Psychological Society.
- Brody, E. M., Kleban, M. H., Lawton, M. P., & Silverman, H. A. (1971). Excess disabilities of mentally impaired aged: impact of individualized treatment. *Gerontologist*, 11, 124-133.
- Bunn, F., Goodman, C., Sworn, K., Rait, G., Brayne, C., Robinson, L., . . . Iliffe, S. (2012). Psychosocial factors that shape patient and carer experiences of dementia diagnosis and treatment: A systematic review of qualitative studies. *PLoS Medicine*, 9(10), 1-12. doi: 10.1371/journal.pmed.1001331
- Bush, T. (2007). Cognitive assessment of older adults with Alzheimer's disease. *Nursing Times*, 103, 31. Retrieved from <http://www.nursingtimes.net/use-of-cognitive-assessment-with-alzheimers-disease/201668.fullarticle>
- Caddell, L. S., & Clare, L. (2010). The impact of dementia on self and identity: A systematic review. *Clinical Psychology Review*, 30, 113-126. doi: 10.1016/j.cpr.2009.10.003
- Cahill, S., Begley, E., Topo, P., Saarikalle, K., Macijauskiene, J., Budraitiene, A., . .

- . Jones, K., (2004). "I know where this is going and I know it won't go back": Hearing the individual's voice in dementia quality of life assessments. *Dementia*, 3, 313-330. doi: 10.1177/1471301204045163
- Cahill, S. M., Gibb, M., Bruce, I., Headon, M., & Drury, M. (2008). "I was worried coming in because I don't really know why it was arranged". *Dementia*, 7, 175-189. doi: 10.1177/1471301208091157
- Charmaz, K. (2000). Experiencing chronic illness. In G. L. Albrecht, R. Fitzpatrick, & S. C. Scrimshaw (Eds.), *The handbook of social studies in health and medicine* (pp.277-292). London: Sage.
- Cheston, R., & Bender, M. (1999). *Understanding dementia: The man with the worried eyes*. London: Jessica Kingsley.
- Christensen, K., Doblhammer, G., Rau, R., & Vaupel, J. W. (2009). Ageing populations: the challenges ahead. *Lancet*, 374, 1196-1208. doi: 10.1016/S0140-673(09)61460-4
- Clare, L. (2002). We'll fight it as long as we can: Coping with the onset of Alzheimer's disease. *Aging and Mental Health*, 6, 139-148. doi: 1080/13607860220126826
- Clare, L. (2003). Managing threats to self: Awareness in early stage Alzheimer's disease. *Social Science and Medicine*, 57, 1017-1029. doi: 10.1016/S0277-9536(02)00476-8
- Cohen, D., Kennedy, G., & Eisdorfer, C. (1984). Phases of change in the patient with Alzheimer's dementia: A conceptual dimension for defining health care

- management. *Journal of the American Geriatric Society*, 32, 11-15. doi: 10.1111/j.1532-5415.1984.tb05143.x
- Collerton, D., & Domone, R. (2014). Cognitive assessment of people who may be developing dementia. In R. Guss (Ed.), *Clinical psychology in the early stage dementia pathway* (pp. 31-38). Leicester: The British Psychological Society.
- Connell, C. M., Boise, L., Stuckey, J. C., Holmes, S. B., & Hudson, M. L. (2004). Attitudes toward the diagnosis and of dementia family caregivers and primary care physicians. *Gerontologist*, 44, 500-507. doi: 10.1093/geront/44.4.500
- Cotrell, V., & Hooker, K. (2005). Possible selves of individuals with Alzheimer's disease. *Psychology and Aging*, 20, 285-294. doi: 10.1037/0882-7974.20.2.285
- Cotrell, V., & Schulz, R. (1993). The perspective of the patient with Alzheimer's disease: A neglected dimension of dementia research. *The Gerontologist*, 33, 205-211. doi: 10.1093/geront/33.2.205
- Cox, D. (2011). The role of neuropsychological testing in the care of older adults. *BC Medical Journal*, 52, 416-420. Retrieved from <http://www.bcmj.org/articles/role-neuropsychological-testing-care-older-adults>
- Cracknell, R. (2010). The ageing population. In A. Mellows-Facer, (Ed.), *Key issues for the new parliament 2010* (p. 44). London: House of Commons.
- Cullen, B., O'Neill, B., Evans, J. J., Coen, R. F., & Lawler, B. A. (2007). A review of screening tests for cognitive impairment. *Journal of Neurology*,

- Neurosurgery and Psychiatry*, 78, 790-779. Retrieved from <http://jnp.bmj.com/content/78/8/790.long>
- Davis, D. H. J., Creavin, S. T., Yip, J. L. Y., Noel-Storr, A. H., Brayne, C., & Cullum, S. (2015). Montreal Cognitive Assessment for the diagnosis of Alzheimer's Disease and other dementias. *Cochrane Database of Systematic Reviews*, 10. doi: 10.1002/14651858.CD010775.pub2
- Data Protection Act, 29 HMSO. § 1 (1998).
- De Boer, M. E., Hertogh, C. M. P. M., Dröes, R., Riphagen, I. I., Jonker, C., & Eefsting, J. A. (2007). Suffering from dementia, the patient's perspective: A review of the literature. *International Psychogeriatrics*, 19, 1021-1039. doi: 10.1017/S1041610207005765
- Department of Health. (2009). *Living well with dementia: A national strategy*. London: Department of Health.
- Downs, M., Clare, L., & Anderson, E. (2008). Dementia as a biopsychosocial condition: implications for practice and research. In R. Woods & L. Clare (Eds.), *Handbook of the clinical psychology of ageing* (2nd ed., pp. 144-159). Chichester: Wiley.
- Elliott, R., Fisher, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215-229. Retrieved from <http://www.ingentconnect.com/content/>
- Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). Mini-mental State: A practical method of grading the cognitive state of patients for the clinician.

Journal of Psychiatric Research, 12, 189-198. doi:10.1016/0022-3956(75)90026-6

Gillies, B. A. (2000). A memory like clockwork: Accounts of living with dementia.

Aging and Mental Health, 4, 366-374. doi: 10.1080/713649961

Gillies, B. A. (2001). The experience of living with dementia. *International Journal of Geriatric Psychiatry*, 16, 111-112. doi: 10.1002/1099-

1166(200101)16:1<111::AID-GPS275>3.0.CO;2-X

Glaser, B. G. (1978). *Theoretical Sensitivity: Advances in the Methodology of Grounded Theory*. Mill Valley, CA: Sociology Press.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine Publishing.

Green, J., & Thorogood, N. (2009). *Qualitative methods for health research* (2nd. Ed.), London: Sage.

Green, R. C., Cupples, L. A., Go, R., Benke, K. S., Edeki, T., Griffith, P. A., . . .

Farrer, L. A. (2002). Risk of dementia amongst white African American relatives of patients with Alzheimer's disease. *Journal of the American Medical Association*, 287, 329-336. doi:10.1001/jama.287.3.329

Hamer, M., & Chida, Y. (2009). Physical activity and risk of neurodegenerative disease: A systematic review of prospective evidence. *Psychological Medicine*, 39, 3-11. doi: 10.1017/S0033291708003681

Harding, N., & Palfrey, C. (1997). *The social construction of dementia: Confused professional?* London: Jessica Kingsley Publishers.

Harman, G., & Clare, L. (2006). Illness representations and lived experience in

- early-stage dementia. *Qualitative Health Research*, 16, 484-502. doi: 10.1177/1049732306286851
- Harris, P. B. (2010). Dementia and dementia care: The contributions of a psychosocial perspective. *Sociology Compass*, 4, 249-262. doi: 10.1111/j.1751-9020.2010.00276.x
- Harris, P. B., & Sterin, G. J. (1999). Insider's perspective: Defining and preserving the self of dementia. *Journal of Mental Health and Aging*, 5, 241-256.
Retrieved from <http://adlib.alzheimers.org/adear/alzdb/fullrec.aspx?id=07860>
- Hefferon, K., & Gil-Rodriguez, E. (2011). Interpretative phenomenological analysis. *The Psychologist*, 24, 756-759.
- Help the Aged. (2009). *One voice: Shaping our aging society*. London: Help the Aged.
- Henwood, K. L., & Nicolson, P. (1995). Qualitative research. *The Psychologist*, 8, 109-129.
- Hodge, S., & Hailey, E. (2013). *English national memory clinics audit report* (Publication No. CCQI158). London: Royal College of Psychiatrists.
Retrieved from www.rcpsych.ac.uk/memoryclinicsaudit
- Holst, G., & Hallberg, I. R. (2003). Exploring the meaning of everyday life, for those suffering from dementia. *American Journal of Alzheimer's Disease and Other Dementias*, 18, 359-365. doi: 10.1177/153331750301800605
- Howitt, D., & Cramer, D. (2011). *Introduction to research methods in psychology* (3rd. ed.), Harlow: Pearson.

- Hsieh, S., Schubert, S., Hoon, C., Mioshi, E., & Hodges, J. R. (2013). Validation of the Addenbrookes Cognitive Examination III in frontotemporal dementia and Alzheimer's disease. *Dementia and Geriatric Cognitive Disorders*, 36, 242-250. doi: 10.1159/000351671
- Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15, 1277-1288. doi: 10.1177/1049732305276687
- Hugh-Jones, S., & Gibson, S. (2012). Collecting your data. In C. Sullivan, S. Gibson, & S. Riley (Eds.), *Doing your qualitative psychology project* (pp. 101-126). London: Sage.
- Husband, H. J. (1999). The psychological consequences of learning of a dementia diagnosis. *Aging and Mental Health*, 3, 179-183. doi: 10.1080/13607869956352
- Keady, J., & Gilliard, J. (1999). The early experience of Alzheimer's disease: implications for partnership and practice. In T. A., Adams, & C. L. Clarke (Eds.), *Dementia care: Developing partnerships in practice*. London: Baillière Tindall.
- Keady, J., & Gilliard, J. (2002). Testing times: The experience of neuropsychological assessment for people with suspected dementia. In P. B. Harris (Ed.), *The Person with Alzheimer's disease: Pathways to understanding the experience*. Baltimore, ML: John Hopkins University Press.
- Keady, J., & Nolan, M. (1994). Younger onset dementia: developing a longitudinal

- model as the basis for a research agenda and as a guide to interventions with sufferers and carers. *Journal of Advanced Nursing*, 19, 659-669. doi: 10.1111/j.1365-2648.tb01136x
- Keady, J., & Nolan, M. (1995a). IMMEL: assessing coping responses in the early stages of dementia. *British Journal of Nursing*, 4, 309-314. Retrieved from <http://content.ebscohost.com.ueaezproxy.uea.ac.uk:2048>
- Keady, J., & Nolan, M. (1995b). IMMEL 2: working to augment coping responses in early dementia. *British Journal of Nursing*, 4, 377-381. Retrieved from <http://content.ebscohost.com.ueaezproxy.uea.ac.uk:2048>
- Kitwood, T. (1990). The dialectics of dementia: with particular reference to Alzheimer's disease. *Ageing and Society*, 10, 177-196. doi:10.1017/S0144686X00008060.
- Kitwood, T. (1993). Towards a theory of dementia care: the interpersonal process. *Ageing and Society*, 13, 51-67. doi: 10.1017/S0144686X00000647
- Kitwood, T. (1997a). The dementia experience. *Aging and Mental Health*, 1, 13-22. doi: 10.1080/13607869757344
- Kitwood, T. (1997b). *Dementia reconsidered: The person comes first*. Maidenhead: Open University Press.
- Kitwood, T., & Benson, S. (Eds.). (1995). *The New Culture of Dementia Care*. London: Hawker.
- Kitwood, T., & Bredin, K. (1992). Toward a theory of dementia care: personhood and well-being. *Ageing and Society*, 12, 269-287. doi:10.1017/S0144686X0000502X.

- Koppel, O. S. B., & Dallos, R. (2007). The development of memory difficulties: A journey into the unknown. *Dementia*, 6, 193-213. doi: 10.1177/1471301207080363
- Lee, S. M., Roen, K. R., & Thornton, A. (2014). The psychological impact of a diagnosis of Alzheimer's disease. *Dementia*, 13, 289-305. doi: 10.1177/1471301213497080
- Langdon, S. A., Eagle, A., & Warner, J. (2007). Making sense of dementia in the social world: A qualitative study. *Social Science and Medicine*, 64, 989-1000. doi: 10.1016/j.socscimed.2006.10.029
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer
- Leventhal, H., Nerenz, D., & Steele, D. J. (1984). Illness representations and coping with health threats. In S. Baum, S. E. Taylor, & J. E. Singer (Eds.), *Handbook of health psychology* (Vol. 4, pp. 219-252). Hillsdale, NJ: Lawrence Erlbaum.
- Luchsinger, J. A., Reitz, C., Honig, L. S., Tang, M. X., Shea, S., & Mayeux, R. (2005). Aggregation of vascular risk factors and risk incident Alzheimer's disease. *Neurology*, 65, 545-551. doi: 10.1212/01.wnl.0000172914.08967.dc
- Lyman, K. (2000). Bringing the social back in: A critique of the biomedicalization of dementia. *The Gerontologist*, 29, 597-605.
- MacQuerrie, C. R. (2005). Experiences in early stage Alzheimer's disease: Understanding the paradox of acceptance and denial. *Aging and Mental Health*, 9, 430-441. doi:10.1080/13607860500142853

- Manthorpe, J., Samsi, K., Campbell, S., Abley, C., Keady, J., Bond, J., . . . Iliffe, S. (2013). From forgetfulness to dementia: Clinical and commissioning implications of diagnostic experiences. *British Journal of General Practice*, 63, 69-75. doi: 10.3399/bjgp13X660805
- Menne, H. L., Kinney, J. M., & Morhardt, D. J. (2002). 'Trying to continue to do as much as they can do': Theoretical insights regarding continuity and meaning making in the face of dementia. *Dementia*, 1, 367-382. doi: 10.1177/147130120200100308
- Morris, R. G., Worsley, C., & Matthews, D. (2000). Neuropsychological assessment in older people: Old principles and new directions. *Advances in Psychiatric Treatment*, 6, 362-372. doi: 10.1192/apt.6.5.362
- Morrison, V. (2008). Ageing and physical health. In R. Woods & L. Clare (Eds.), *Handbook of the clinical psychology of ageing* (2nd ed., pp. 57-74). Chichester: Wiley.
- Morse, J. M. (2000). Determining sample size. *Qualitative Health Research*, 10, 3-5. doi: 10.1177/104973200129118183
- Mortimer, J. A., Snowden, D. A., & Markesbery, W. R. (2003). Head circumference, education and risk of dementia: Findings from the Nun study. *Journal of Clinical Experimental Neuropsychology*, 25, 671-679.
- National Institute for Health and Clinical Excellence. (2006). *Dementia: Supporting people with dementia and their carers*. London: National Institute for Health and Clinical Excellence. Retrieved from <http://www.nice.org.uk/nicemedia/pdf/CG042NICEGuideline.pdf>

- Oeppen, J., & Vaupel, J. W. (2002). Demography: Broken limits to life expectancy. *Science*, 296, 1029-1031. doi:10.1126/science.1069675
- Office for National Statistics. (2012). *Population ageing in the United Kingdom, its constituent countries and the European Union*. Retrieved from http://www.ons.gov.uk/ons/dcp171776_258607.pdf
- Office for National Statistics. (2013). *General lifestyle survey 2011*. Retrieved from <http://www.ons.gov.uk/ons/rel/ghs/general-lifestyle-survey/2011/index.html>
- Orlinsky, D., Grawe, K., & Parks, B. (1994). *Handbook of psychotherapy and behaviour change* (4th ed.). New York: Wiley.
- Ostwald, S. K., Duggleby, W., & Hepburn, K. W. (2002). The stress of dementia: View from the inside. *American Journal of Alzheimer's Disease and Other Dementias*, 17, 303-312. doi: 10.1177/153331750201700511
- Park, C. L., & Folkman, S. (1997). Meaning in the context of stress and coping. *Review of General Psychology*, 1, 115-144. doi: 10.1037/1089-2680.1.2.115
- Patterson, C., Feightner, J., Garcia, A., & MacKnight, C. (2007). General risk factors for dementia: A systemic evidence review. *Alzheimer's and Dementia*, 3, 341-347. doi: 10.1016/j.jalz.2007.07.001
- Pearce, A., Clare, L., & Pistrang, N. (2002). Managing sense of self: Coping in the early stages of Alzheimer's disease. *Dementia*, 1, 173-192. doi: 10.1177/147130120200100205
- Phinney, A. (1998). Living with dementia: From the patient's perspective. *Journal of Gerontological Nursing*, 24, 8-15. doi: 10.3928/0098-9134-19980601-06
- Pratt, R., & Wilkinson, H. (2001). "Tell me the truth". *The effect of being told the*

diagnosis of dementia from the perspective of the person with dementia.

Stirling” The Mental Health Foundation.

- Pratt, R., & Wilkinson, H. (2003). A psychosocial model of understanding the experience of receiving a diagnosis of dementia. *Dementia*, 2, 181-199. doi: 10.1177/1471301203002002004
- Preston, L., Marshall, A., & Bucks, R. A. (2007). Investigating the ways that older people cope with dementia: A qualitative study. *Aging and Mental Health*, 11, 131-143. doi: 10.1080/13607860600844572
- Prince, M., Bryce, R., & Ferri, (2011). *World Alzheimer Report 2011: the benefits of early diagnosis and intervention*. London: Alzheimer’s Disease International.
- Robertson, A. (1990). The politics of Alzheimer’s disease: A case study in apocalyptic demography. *International Journal of Health Sciences*, 20, 429-442. doi: 10.2190/c8ae-nyc1-2r98-mhp1
- Robillard, A. (2007). Clinical diagnosis of dementia. *Alzheimer's and Dementia*, 3, 292-298. doi: <http://dx.doi.org/10.1016/j.jalz.2007.08.002>
- Robinson, P., Ekman, S. L., & Wahlund, L. O. (1998). Unsettled, uncertain and striving to understand: Toward an understanding of the situation of persons with suspected dementia. *International Journal of Ageing and Human Development*, 47, 143-161. doi: 10.2190/PJY4-WB9F-CN2D-1P2B
- Robinson, L., Clare, L., & Evans, K. (2005). Making sense of dementia and adjusting to loss: Psychological reactions to a diagnosis of dementia in couples. *Aging and Mental Health*, 9, 337-347. doi: 10.1080/13607860500114555

- Robinson, L., Gemski, A., Abley, C., Bond, J., Keady, J., Campbell, S., . . .
- Manthorpe, J. (2011). The transition to dementia: Individual and family experiences of receiving a diagnosis: A review. *International Psychogeriatrics*, 23, 1026-1043. doi: 0.1017/S1041610210002437
- Sabat, S. R. (1994). Excess disability and malignant social psychology: A case study of Alzheimer's Disease. *Journal of Community and Applied Social Psychology*, 4, 157-166. doi: 10.1002/casp.2450040303
- Sabat, S. R. (2002). Surviving manifestations of selfhood in Alzheimer's disease: A case study. *Dementia*, 1, 25-36. doi: 10.1177/147130120200100101
- Sabat, S. R., & Harré, R. (1992). The construction and deconstruction of self in Alzheimer's disease. *Ageing and Society*, 12, 443-461. doi: 10.1017/S0144686X00005262
- Samsi, K., Abley, C., Campbell, S., Keady, J., Manthorpe, J., Robinson, L., . . .
- Bond, J. (2014). Negotiating a labyrinth: Experiences of assessment and diagnostic journey in cognitive impairment and dementia. *International Journal of Geriatric Psychiatry*, 29, 58-67. doi: 10.1002/gps.3969
- Smith, A. P., & Beattie, L. B. (2001). Disclosing a diagnosis of Alzheimer's disease: Patient and family experiences. *The Canadian Journal of Neurological Sciences*, 28, S67-S71. Retrieved from <http://www.cnsfederation.org/cnsf/cjns/>,
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, method and research*. London: Sage.
- Smith, A. P., King, E., Hindley, N., Barnetson, L., Barton, J., & Jobst, K. A. (1998).

The experience of research participation and value of diagnosis in dementia:
Implications for practice. *Journal of Mental Health*, 7, 309-321. doi:
10.1080/09638239818120

Smith, J. A., & Osborn, M. (2008). Interpretative phenomenological analysis. In J.
A. Smith, (Ed.), *Qualitative psychology: A practical guide to research
methods* (2nd. ed., pp. 53-80). London: Sage.

Snowdon, D. A. (2003). Healthy aging and dementia: Findings from the nun study.
Annals of Internal Medicine, 139, 450-454. Retrieved from
<http://ovidsp.tx.ovid.com>

Sosa-Ortiz, A. L., Acosta-Castillo, I., & Prince, M. J. (2012). Epidemiology of
dementias and Alzheimer's disease. *Archives of Medical Research*, 43, 600-
608. doi: 10.1016/j.arcmed.2012.11.003

Spector, A., & Orrell, M. (2010). Using a biopsychosocial model of dementia as a
tool to guide clinical practice. *International Psychogeriatrics*, 22, 957-965.
doi: 10.1017/S1041610210000840

St Clair, D., Rennie, M., Slorach, E., Norrman, J., Yates, C., & Carothers, A. (1995).
Apolipoprotein E epsilon 4 allele is a risk factor for familial and sporadic
presenile Alzheimer's disease in both homozygote and heterozygote carriers.
Journal of Medical Genetics, 32, 642-644. Retrieved from
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1051642/pdf/jmedgene00275-0060.pdf>

Steeman, E., De Casterlé, B., Godderis, J., & Grypdonck, M. (2006). Living with
early-stage dementia: a review of qualitative studies. *Journal Of Advanced*

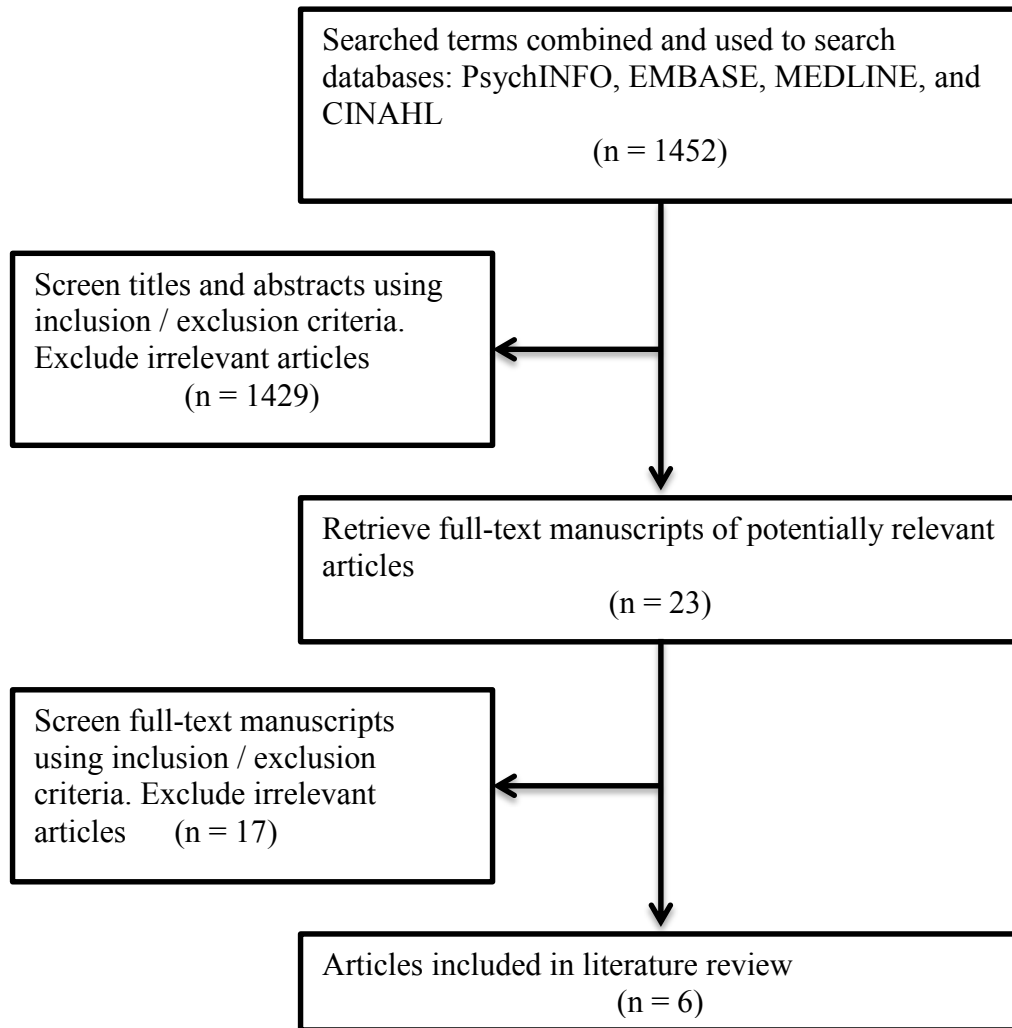
- Nursing*, 54, 722-738. doi:10.1111/j.1365-2648.2006.03874.x
- Stroebe, M. S., Schut, H. A. W. & Stroebe, W. (1998). Trauma and grief: A comparative analysis. In J. H. Harvey (Eds.), *Perspectives on loss: A sourcebook* (pp. 81-96). Washington: Taylor & Francis.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed.), Thousand Oaks, CA: Sage.
- United Nations, Department of Economic and Social Affairs, Population Division. (2013). *World population ageing 2013* (UN Publication No. ST/ESA/SER.A/348). New York: United Nations.
- Valenzuela, M. J., Sachdev, P. (2006). Brain reserve and dementia: a systematic review. *Psychological Medicine*, 36, 441-454.
doi:10.1017/S0033291706007744
- Visser, P. J., Vos, S., van Rossum, I., & Scheltens, P. (2012). Comparison of International Working Group criteria and National Institute on Aging–Alzheimer’s Association criteria for Alzheimer’s disease. *Alzheimer's & Dementia*, 8, 560-563. doi:10.1016/j.jalz.2011.10.008
- Wang, H.-X., Karp, A., Winblad, B., & Fratiglioni, L. (2002). Late-life engagement in social and leisure activities is associated with decreased risk of dementia: A longitudinal study from the Kungsholmen project. *American Journal of Epidemiology*, 155, 1081-1087. doi: 10.1093/aje/155.12.1081
- Westbrook, D., Kinnerley, H., & Kirk, J. (2010). *An Introduction to Cognitive Behaviour Therapy: Skills and Applications*. London: Sage.

- Whitmer, R. A., Sidney, S., Selby, J., Johnston, S. C., & Yaffe, K. (2005). Midlife cardiovascular risk factors and risk of dementia in late life. *Neurology*, 4, 277-281. Retrieved from <http://ovidsp.tx.ovid.com/sp-3.14.0b/>
- Willig, C. (2008). *Introducing qualitative research in psychology* (2nd ed.). Maidenhead: Open University Press.
- Willis, R., Chan, J., Murray, J., Matthews, D., & Banerjee, S. (2009). People with dementia and their family carers' satisfaction with a memory clinic: A qualitative evaluation generating quality indicators for dementia care. *Journal of Mental Health*, 18, 26-37. doi: 10.1080/09638230701529681
- Woods, R. T. (2001). Discovering the person with Alzheimer's disease: cognitive, emotional and behavioural aspects. *Aging and Mental Health*, 5(Supplement 1), S1-S16. doi: 10.1080/1360786012004756
- World Health Organisation. (2011). *Global health and aging* (NIH Publication No. 11-7737). Retrieved from http://www.who.int/ageing/publications/global_health.pdf
- World Health Organisation. (2012a). *Dementia* (WHO Factsheet No. 362). Retrieved from <http://www.who.int/mediacentre/factsheets/fs362/en/>
- World Health Organisation. (2012b). *Dementia: A public health priority*. United Kingdom: World Health Organisation. Retrieved from http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf?u
- Wright, J. H., & Davis, D. (1994). The therapeutic relationship in cognitive-behavioural therapy: Patients perceptions and therapists responses. *Cognitive and Behavioural Practice*, 1, 25-45. doi:10.1016/S1077-7229(05)80085-9

- Yardley, L. (2000). Dilemmas in qualitative research. *Psychology and Health*, 15, 215-228. doi:10.1080/08870440008400302
- Yardley, L., (2008). Demonstrating validity in qualitative psychology. In J. A, Smith (Ed.). *Qualitative psychology: A practical guide to research methods* (pp. 235-251). London: Sage.
- Yip, A. G., Brayne, C., & Matthews, F. E. (2006). Risk factors for incident dementia in England and Wales: The medical research council cognitive function and ageing study. A population-based nested case-control study. *Age and Ageing*, 35, 154.160. doi: 10.1093/ageing/afj030

Appendices

Appendix A: Literature Review Search Process



Appendix B: Studies included in Literature Review

Study	Type of study Aim of study	Participants	Data Collection Data Analysis	Findings
1. Cahill, Gibb, Bruce, Headon, & Drury (2008)	Mixed methods Memory clinic service evaluation: examine patient and family caregivers experiences of attending memory clinic cognitive assessment	N=56 P=28 (variety dementia diagnoses) C=28	Semi-structured questionnaire (fixed choice and open-ended questions) P interviewed twice T1 prior appointment and T2 after appointment C interviewed once T1 as P. Interviewed separately 10-15 min. per interview TA	Attitudes to attending clinic = uncertain about process/assessment Attitudes to cognitive assessment = P=positive exp>negative exp.
2. Keady & Gilliard (2002)	Qualitative Lived experience of AD, mapping process of becoming person with dementia. Taken from interviews, which aimed to explore: experiences of dementia & coping, when and how professional help is sought, supporter stress and coping, view of resources.	N=15 with mild AD (plus supporters) 6 from study Keady & Nolan, 1995)	Semi-structured joint interviews. Interviewed together once ≥6mths diagnosis. Max 45 min interview GT CCA	Assessment: 1) seeking help: a) acknowledging the challenge, b) playing the game, c) future options Highlighted anxiety and distress about being assessed and outcome
3. Manthorpe, Samsi, Campbell, Abley, Keady,	Qualitative (Retrospective and prospective)	N=53 P=27	Semi-structured interviews (8 diagnosis of dementia at	Themes identified: 1)diagnosis sought: belief

Bond, Watts, Robinson, Warner, & Iliffe (2013)	Understand experiences of diagnostic process (accessing services, assessments, treatment decisions and encounters with HP before and after diagnosis of dementia) for patient and carer.	(AD, VaD, MCI) C=26 MP=20	interview; 13 diagnosis by second interview T1 before T2 after diagnostic ax; 6 awaiting diagnosis) unclear length of interview GT CCA	timeliness important; 2) assessment delays matter; 3) setting of assessment matters; 4) professional communication matters
4. Koppel & Dallos (2007)	Qualitative Elicit peoples understanding of development of memory problems over time	N=3 dyads P=3 C=3	Semi-structured interviews (2: before and after assessment) 40-60 min. P & C separate. Only P interview used IPA	1st interview: 'uncertainty': trying to make sense of memory diff; impact on identity; impact on relationships 2 nd interview: experience of memory clinic; continued search for meaning; changing identity
5. Samsi, Abley, Keady, Manthorpe, Robinson, Watts, & Bond (2014)	Qualitative Explore patient and carer experiences of diagnostic pathway	Sample same as Manthorpe et al, 2013) N=53 P=27 (AD, VaD, MCI) C=26 MP=20	Semi-structured interviews (8 diagnosis of dementia at interview; 13 diagnosis by second interview T1 before T2 after diagnostic ax; 6 awaiting diagnosis) GT CCA	Themes: 1) Initial service encounters: a) GP positive experience b) primary care as gateway 2) Assessment processes: a) confusing referral process, b) entering the labyrinth, confusing, anxiety provoking, c)

				waiting times 3-9 mths, d) prolonged anxiety 3) Diagnosis disclosure: a) emotional experience, b) lack of information 4) Long-term management: a) memory training, b) planning, c) dashed expectations
6. Willis, Chan, Murray, Matthews, & Banerjee (2009)	Qualitative Explore patient and carer experiences of memory clinic services	N=31 P=16 C=15 MP=15	Semi-structured interviews Interviewed once, separately. CoCA	Themes: Cognitive assessment experiences small part of study 1) Assessment experienced as anxiety-provoking, performance worry 2) Clinician relationship reassuring : insensitive

Note: Participants: AD = Alzheimer's disease; C = Carer/family member; MCI = Mild cognitive impairment; MP = Matched pair; P = Person with possible dementia/dementia; VaD = Vascular dementia.

Data Analysis: CCA = Constant comparative analysis; CoCA = Conventional content analysis; GT = Grounded theory; IPA = Interpretative phenomenological analysis; TA = Thematic analysis

Appendix C: NHS Research Ethics Committee Approval



Health Research Authority

NRES Committee East of England - Cambridge Central

Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0115 883 9309

20 October 2014

Mrs Chantel Robinson
Trainee Clinical Psychologist
Cambridgeshire and Peterborough NHS Foundation Trust
Postgraduate Office, Room 2.30, Elizabeth Fry Building
Faculty of Medicine and Health Sciences
University of East Anglia,
Norwich
NR4 7TJ

Dear Mrs Robinson

Study title:	The journey from uncertainty to certainty and back again: An exploratory study of patient experiences of being assessed for suspected Dementia, using Interpretative Phenomenological Analysis
REC reference:	14/EE/1130
IRAS project ID:	151706

The Research Ethics Committee reviewed the above application at the meeting held on 10 October 2014. Thank you and Dr Susan Pullan for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Tracy Leavesley, NRESCommittee.EastofEngland-CambridgeCentral@nhs.net

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on question 2 of 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 contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

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 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).

Summary of discussion at the meeting

Ethical issues raised, noted and resolved in preliminary discussion

Informed consent process and the adequacy and completeness of participant information

The Committee agreed the Participant Information Sheet would benefit from a more detailed description of what the literature says regarding this condition rather than the current details of the applicants but agreed that this was not entirely an ethical issue and would not require amendment.

Social or scientific value; scientific design and conduct of the study

The Committee noted there is a lack of research into this area and agreed this is a valuable study.

Recruitment arrangements and access to health information, and fair participant selection

The Committee discussed the recruitment for the study and noted it is unclear who will send out the first contact to the patient to invite them to take part in the study. Conflicting information states this will come from the clinician at the service or the applicant. The Committee asked the applicants to briefly explain the recruitment process. *The applicants advised the Psychologist to whom the patient has been referred would assess the patient for suitability for the study using the inclusion/exclusion criteria, and if the patient was interested in being invited to take part in the study, they would give their consent to be contacted by the applicants via the Expression of Interest form. The applicants went on to explain they would then contact the patient and discuss the study with them and arrange a time and place for the interview to take place at which time, a formal consent to participate would be taken.*

It was noted the applicant intends to only recruit from the over 60 age group and the Committee considered the applicants may be missing an entire cohort of participants within early onset patients. *When asked this question, the applicants agreed this group could provide a good perspective, but advised they are trying to create a homogenous group in this study, although they may consider a follow up study to include the early onset group of patients.*

Care and protection of research participants; respect for potential and enrolled participants' welfare and dignity

The Committee asked the applicants who would have access to patient files and what information would be retrieved from these files. *The applicants advised the patients would be referred to the service by their GP to be seen by a Psychologist from the service and it was at this point the patient's suitability for the study would be assessed.*

The Committee asked the applicants whether an appropriate referral process was in place in case of any disclosures during the interview. *The applicants confirmed they would signpost a participant to the appropriate services if this situation arose during the interview.*

Other general comments

The Committee agreed this is a good overall study which should be supported.

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		09 May 2014
GP/consultant information sheets or letters [Patient experiences of cognitive assessment - GP Ltr]	1	18 June 2014
Interview schedules or topic guides for participants [Patient experiences of cognitive assessment - Interview Schedule]	1	18 June 2014
IRAS Checklist XML [Checklist_26082014]		26 August 2014
Letter from sponsor		20 August 2014

Letters of invitation to participant [Patient experiences of cognitive assessment - Invite Ltr]	2	16 July 2014
Non-validated questionnaire [CV - Deirdre Williams]		28 August 2014
Participant consent form [Patient experiences of cognitive assessment - Consent Form]	1	18 June 2014
Participant information sheet (PIS) [Patient experiences of cognitive assessment - PIS]	3	19 August 2014
REC Application Form [REC_Form_26082014]		26 August 2014
Referee's report or other scientific critique report [Proposal_review_pass]		29 January 2014
Research protocol or project proposal [Patient experiences of cognitive assessment - Protocol]	3	18 July 2014
Summary CV for Chief Investigator (CI) [Chantel Robinson]		
Summary CV for supervisor (student research) [Kenneth Laidlaw]		

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

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-the-hra/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/>

14/EE/1130	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project.

Yours sincerely



Mrs Carolyn Read
Chair

E-mail: NRESCommitteeEastofEngland-CambridgeCentral@nhs.net

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

"After ethical review – guidance for researchers"

Copy to: Mrs Sue Steel

*Mr Stephen Kelleher, Cambridgeshire and Peterborough NHS
Foundation Trust*

Appendix D: NHS Trust Research and Development Approval

Cambridgeshire and Peterborough NHS Foundation Trust

Understanding children, young people and families
Research and Development Department

29th October 2014

R&D Ref: M00678

Mrs Chantel Robinson
Cambridge and Peterborough Foundation Trust
Postgraduate Office, Room 2.30, Elizabeth Fry Building,
Faculty of Medicine and Health Services
University of East Anglia
Norwich
NR4 7TJ
Norfolk

Joint Research Office
Box 277
Addenbrooke's Hospital
Hills Road
Cambridge
CB2 0QQ

Direct Dial: 01223 256 407 (ext 56407)
E-mail: harriet.nesbitt@cpft.nhs.uk
www.cpft.nhs.uk

Dear Mrs Robinson,

Re: 14/LO/1624 The journey from uncertainty to certainty and back again: An exploratory study of patient experiences of being assessed for suspected Dementia, using Interpretative Phenomenological Analysis

In accordance with the Department of Health's Research Governance Framework for Health and Social Care, all research projects taking place within the Trust must receive a favourable opinion from an ethics committee and approval from the Department of Research and Development (R&D) prior to commencement.

R&D have reviewed the documentation submitted for this project, and has undertaken a **site specific assessment** based on the information provided in the SSI form, and I am pleased to inform you that we have no objection to the research proceeding within CPFT.

Sponsor: University of East Anglia

Funder: N/A

End date: 27/03/2015

Protocol: Version 3.0 dated 18/07/2014

Conditions of Trust Approval:

- The project must follow the agreed protocol and be conducted in accordance with all Trust Policies and Procedures especially those relating to research and data management. Any mobile devices used must also comply with Trust policies and procedures for encryption.
- You and your research team must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice and the Data Protection Act 1998 and are aware of your responsibilities in relation to the Human Tissue Act 2004, Good Clinical Practice, the NHS Research Governance Framework for Health and Social Care, Second Edition April 2005 and any further legislation released during the time of this study.



HQ Elizabeth House, Fulbourn Hospital, Cambridge CB21 5EF.
T 01223 726789 F 01480 398501 www.cpft.nhs.uk

A member of Cambridge University Health Partners

- Members of the research team must have appropriate substantive or honorary contracts with the Trust prior to the study commencing. Any additional researchers who join the study at a later stage must also hold a suitable contract.
- You and your research team must provide to R&D, as soon as available, the date of first patient first visit.

If the project is a clinical trial under the European Union Clinical Trials Directive the following must also be complied with:

- the EU Directive on Clinical Trials (Directive 2001/20/EC) and UK's implementation of the Directive: The Medicines for Human Use (Clinical Trials) Regulations 2004;
- the EU Directive on Principles and Guidelines for Good Clinical Practice (EU Commission Directive 2005/28/EC); and UK's implementation of the Directive: The Medicines for Human Use (Clinical Trials) Amendment Regulations 2006;

Amendments

Please ensure that you submit a copy of any amendments made to this study to the R&D Department.

Annual Report

It is obligatory that an annual report is submitted by the Chief Investigator to the research ethics committee, and we ask that a copy is sent to the R&D Department. The yearly period commences from the date of receiving a favourable opinion from the ethics committee.

Please refer to our website www.cpft.nhs.uk for all information relating to R&D including honorary contract forms, policies and procedures and data protection.

Should you require any further information please do not hesitate to contact us.

Yours sincerely



Stephen Kelleher
Senior R&D Manager

Appendix E: Research Invitation Letter and Consent to Share Details Form

16th July 2014 (v.2)



Research Invitation Letter

Dear

You are invited to take part in a research study that is interested in understanding people's experiences of having a cognitive assessment. A cognitive assessment involves completing a series of different tasks that assess different thinking abilities. This study is being conducted by a trainee clinical psychologist as part of their course at the University of East Anglia.

Your doctor at [SERVICE] has identified that you recently completed a cognitive assessment. Because of this it is felt that you are in a good position to share your experiences of being assessed.

Please find enclosed an information sheet that provides more detail about the study. Please read this carefully and if you are interested in taking part in the study, complete and sign the reply slip at the bottom of this letter. You can either return this in the stamped addressed envelope provided or hand it back to your memory clinic service. On receipt of the reply slip, a researcher will contact you to arrange to discuss this further.

If you have any questions about the study, please do not hesitate to contact the researcher using the contact details outlined in the attached information sheet.

Yours sincerely

[NAME]
Clinical Psychologist

✂-----

Research Project – “Experiences of a cognitive assessment”

I am interested in taking part in the above research project. I agree to the researcher contacting me using the details below, in order to discuss this further.

Name: _____
Address: _____
Telephone: _____
Signature: _____ Date: _____

Appendix F: Research Information Sheet

19th August 2014 (v.3)



Research Information Sheet

Title: Experiences of cognitive assessment

My name is Chantel Robinson and I am currently a Trainee Clinical Psychologist studying at the University of East Anglia. As part of my doctorate course I am required to conduct a piece of clinically relevant research. During my training I worked within a memory clinic and became interested in understanding what it is like for people when they undergo a cognitive assessment. There is currently little research about people's experience of cognitive assessment and I have therefore decided to research this further.

I would like to invite you to take part in my research study. Before you decide whether or not you would like to take part, I would like to provide you with some information about why the research is being done and what it would involve for you.

Please take time to read the following information carefully. If there is anything that you are not clear about or would like to ask any questions then please feel free to contact me using the details provided at the end of this information sheet.

What is the purpose of this study?

I am interested in finding out about what it is like for people when they undergo a cognitive assessment: their thoughts and feelings about being assessed, the impact this may have on them, and the way they coped with this experience.

Why am I being invited to take part?

I am interested in speaking to people who are aged 60 and over, who have completed a cognitive assessment at the memory clinic, within the past 6 months.

Do I have to take part?

No, participation is completely voluntary. Whether you choose to take part or not will not affect the care or treatment you receive from the service.

What will happen if I decide to take part?

If you are interested in taking part in this study, you will need to confirm your interest by completing and returning the agreement slip at the bottom of the invitation letter. The researcher will then contact you directly to discuss the study further.

You can ask any questions about the study. If you would like to take part then the researcher will arrange to meet you. This can be at either the NHS centre where you have the assessment or in your own home, wherever is most convenient for you. When the researcher meets with you they will check whether you still want to take part and you will be asked to sign a consent form to confirm this. You will be given a copy of the consent form to keep.

What does the study involve?

The research involves completing an interview with the researcher about your experiences of going through a cognitive assessment. You will be asked about your thoughts and feelings about being assessed, the impact this may have had on you, and

the way you coped with this experience. The questions will be broad to allow you to express your own views in your own words. This will last approximately 45 minutes. The interview will be audio-recorded so that your comments are accurately captured. In addition to the information collected from the interview, I will also ask consent to collect some background information from your medical records (e.g. your age, assessment outcome). I will also ask consent to let your GP know that you are participating in my research study.

What would happen if I said yes then changed my mind?

You are free to withdraw from the study at anytime and without giving a reason. A decision to withdraw at anytime will not affect the treatment you receive from the service. If you decide to withdraw, all information you have provided will be destroyed, although this would not be possible once the study report has been written up.

What happens to the information you have about me?

The interview will be recorded onto a digital audio-recorder. This will then be transferred into a password protected storage device and deleted from the recorder. Your interview will then be typed up word for word into a written document by the researcher who interviewed you. At this point your name will be replaced with a code and any information that may identify you will be removed so your information remains anonymous and you cannot be identified from your transcript.

The written transcript will be kept secure and confidential. Excerpts of what you say may be included in the final research report, however any information used will already have been anonymised to ensure that you cannot be identified from what you have said. You will be asked if you would like to receive a summary report of the research findings. If you would like this, then a written summary will be sent to you once the study has been completed.

When the study is completed the transcript of your interview will be kept in a locked storage unit at the University of East Anglia for a period of 10 years, in line with current policy. The transcript will then be destroyed.

Will my details in the study be kept confidential?

All information that is collected about you during the course of the research will be kept strictly confidential, and any information about you that leaves the NHS premises will have your name and address removed so that you cannot be recognised.

The only time we would need tell someone else about something you said is if we thought you or another person were at risk of harm. If this were to happen the researcher would aim to discuss this with you first.

What are the possible disadvantages of taking part?

Because the study focuses on exploring your experiences of undergoing a cognitive assessment, there is a possibility that the topics discussed may be upsetting for you. If this were to happen, the researcher will take every step to reduce any upset that you may experience. At any point you may stop the interview. You are also free to decide whether or not you would like to answer or talk about the interview questions/topics raised.

What are the possible benefits of taking part?

The results from this study will help us to understand more about what it is like to undergo a cognitive assessment. Whilst taking part in the study will not affect the treatment you receive, your comments may benefit others in the future.

What will happen to the results from this study?

The results will be written up in the form of research project report that the researcher has to complete as part of the course requirements for the doctoral programme in clinical psychology. It will be submitted to the University of East Anglia. The results may also be published in academic journals. You will not be identified in any of these documents.

Who has reviewed the research study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, so that your interests are protected. This study has been reviewed and given a favourable opinion by [NAME] Research Ethics Committee.

What if there is a problem?

If you have a concern with any aspect of the study then you should contact:

Dr. Sian Coker (Research Director)

Doctoral Programme in Clinical Psychology
School of Medicine, Health Policy and Practice
University of East Anglia
Norwich
NR4 7TJ

Tel: (01603) 593544

If you remain unhappy and wish to complain formally you can do this through the NHS complaints procedure by contacting the local Patient Advice and Liaison Service (01480) 398555.

Further information and contact details

Further information about this study may be obtained from:

Chantel Robinson (Trainee Clinical Psychologist)
Room 2.30, Elizabeth Fry Building
Faculty of Medicine and Health Sciences
University of East Anglia
Norwich, NR4 7TJ
Email: Chantel.Williams@uea.ac.uk

Research Supervisor

Professor Ken Laidlaw
(same address as above)

Thank you for taking time to read this information sheet it is very much appreciated.

Appendix G: Consent Form

18th June 2014 (v.1)



Consent Form

Title of Project:

Participant Number:

Please initial box

1. I confirm that I have read and understand the information sheet dated 19.08.14 (v.3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. I am aware that if the researcher is concerned about the impact that having a neuropsychological assessment is having on me, they may inform me about appropriate services.
4. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from the University of East Anglia, from regulatory authorities or from the NHS trust, where it is relevant to taking part in this research. I give permission for these individuals to have access to my data.
5. I agree to the interview being digitally audio-recorded.
6. I agree that anonymised quotes from my interview can be used in final reports and publications.
7. I agree to take part in the above study.
8. I give permission to the research team to inform my GP about my participation in the above study.
9. I would like to be sent a summary of the research results when the study has finished.

☐☐☐☐☐☐☐☐☐

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

Appendix H: Interview Schedule

18th June 2014 (v.1)



Interview Schedule

Questions

Tell me about your experiences of going through a neuropsychological assessment?

Prompt: What was it like for you?

Prompt: People have mixed emotions / what did you expect / was it like that

Prompt: What did you think about it?

Prompt: What did it mean to you as a person to go through the assessment?

How did you feel about being assessed?

Prompt: What emotions did you experience?

Prompt: What was it like to feel like that? Was that something you expected to feel?

What does it mean to you to go through this assessment process?

Prompt: For some people reminds them of previous situations (school) being assessed

Prompt: What was it like for you / what was it like to think/feel that?

Prompt: What feelings/thoughts did you have about being assessed?

How did you cope with being assessed?

Prompt: What helped you manage the experience/ your emotions about it

Prompt: When you did that what happened? Did it help?

Prompt: How would you usually cope with situations? What was the same/different about this situation.

Is there anything else that you would like to say about your assessment experience?

Appendix I: GP Letter



18th June 2014 (v.1)

Date

Dear Dr (Name),

Research Study: Experiences of neuropsychological assessment

Name of Researcher: Chantel Robinson (Trainee Clinical Psychologist)

This is to inform you that your patient/client has recently agreed to join the study titled: "The journey from uncertainty to certainty and back again: An exploratory study of patient experiences of being assessed for suspected Dementia, using Interpretative Phenomenological Analysis". This study aims to develop an in-depth understanding of how people make sense of, adapt to and cope with undergoing a neuropsychological assessment for suspected dementia.

I met with (name) on (date) to conduct an interview about his/her experiences of undergoing a neuropsychological assessment at the memory clinic [site]. The study is a research study and does not involve any psychological intervention.

If you would like any further information, please do not hesitate to contact me, or Professor Kenneth Laidlaw (Tel: (01603) 593600; email: chantel.williams@uea.ac.uk; kenneth.laidlaw@uea.ac.uk).

We will be happy to discuss any questions that you might have.

Yours sincerely,

Chantel Robinson
Trainee Clinical Psychologist

Supervised by Professor Kenneth Laidlaw (Clinical Psychology Doctoral Course Director).

Appendix J: Individual Case Analysis - Example of Exploratory Coding and Developing Emergent themes

Extract from "Janet's" interview

98 Questions performance Not knowing	any more" cos you...you've proved a point really...erm...so there isn't any positive feedback...well no feedback (laughs) during it erm well not really...you just...DON'T KNOW...don't know whether you're doing right or not...mmmm	uncertainty about performance level of feedback no reference point waiting to know how doing testing & mystery
100	I: and what was that like for you	
101		
102		
103 Professional in control Joking	P: erm...well it's...it's NOT very nice because...it's...when you're NERVOUS it's always good to have some positive...feedback...about...you're doing ok really or...well I think I was told...well yeah I was very aware that it was being timed and may be it was just my insecurities about it rather than...well I don't know (pause) I'm sure it's not their fault...doing their job I'm sure, well she said that, but you know...so	clueless in privileged position (holder of knowledge/information)
104	nice...talking...listening...then NOTHING, well I'm not saying she didn't speak, of course she did, but well yeah, no feedback and more anxiety, and they must know mustn't they, oh I don't know may be it was me but yeah...I DID feel...well yeah it was a bit like a driving test where the driving erm...tester isn't able to say	under sensitivity wants positive feedback as reassurance lack of responsiveness - under pressure ? not sure if other people perform conflict to test experience? did and psychologist = yeah, well ? still feeling uncomfortable → no feedback = ↑ anxiety not knowing → terms of reference part experience of being tested awareness of it
105		
106		
107		
108		
109		
110		
111		
112		
113		
114 Testing Agree		

ambiguity of driving test → not in charge of where you're → being directed.
 not in control.

115	anything to you during it...you know...no feedback no NOTHING	test is cold, removed just
116	just instructions of how to...you when to turn...and well it was a bit	instructions, no feedback
117	like that really for me you know it weren't, it wasn't	no guidance = threatening
118	a...relaxed...time it was a TEST (pause) and a very important test	not relaxing, too V. important
119	(said quietly)...for me...yeah and well I suppose erm I am pretty	process emphasised test
120	insecure you know as I said you know I was ill with depression	i.e. controlled test
121	err... when I left work...when I finished work and that has HAD a	trying to make sense of feeling
122	long erm lasting result in how I am how insecure I am and	anxious → ? justifying to reassure
123	err...you know...feeling of being judged and erm all those sorts of	tests = being judged
124	insecurities, erm yeah that just...erm...the assessment...confirmed	? professional as judging → control
125	really HOW you know...I felt about myself...that I	maybe justifying insecurity
126	FEEL, erm...alright you know certainly still worried about my erm	as problem with self → not clear
127	MEMORY I suppose doing those tasks and not being able to err	hesitant in terms of about
128	(pause) do some of the...you know running out of time you	impact of assessment
129	know...JUST CONFIRMED that my memory is RUBBISH and you	? perhaps find it hard to criticise
130	know that...I couldn't do it (pause) (pause) well they are judging	experience of assessment
131	in some ways, judging you...aren't they, that's the point mmmm it's	subjective experience used as
132	a TEST (laughs)	evidence → i.e. confirming negative self belief

→ saying how vulnerable
 → past and current fears same
 past + present these uses

professional
 no feedback
 being assessed
 feeling judged
 by others
 other in control
 rationalising experience
 judging / appraising own performance

133	I: and what did that mean to you...?	
134	P: well certainly afterwards it was erm, I suppose not...so much	appraisis
135	during it as you're so...I was so anxious about it, you know, I didn't	performance
136	FEEL it at the time, but <u>certainly afterwards</u> I felt well you know,	
137	<u>"that's confirmation that I've got dementia", I was planning the</u>	thinking
138	rest of my life, you know how are we going to well you know	ahead
139	WORK with THIS erm, so yeah erm, I think there were two weeks	future
140	before the end, before I got the feedback and well they were...so	planning
141	they were rotten two weeks REALLY rotten and there was some	
142	err you at the end well "if you feel you want to discuss anything	increased
143	well get in touch" those sorts of things but...but you don't (signs)	uncertainty
144	(pause) it's obvious they can't say anything...well not until later	
145	I: mmmm...ok...obvious they can't say anything...can...?	empty
146	P: (interrupts) well not obvious...well yeah...they have to say it	places
147	don't they, you know "get in touch", but what you...what you really	
148	want to know...really it "how did I do", "is it dementia", and well	

during appraisal = feelings of anxiety, most salient → focus on experience of being afterwards time to reflect on experience
 after assessment → what is real appraised performance based on experience = not have demands
 uncertainty → planning preparation for confirmation of fears
 → begins with potential threat i.e. problem solving
 waiting = ↑ uncertainty / anxiety
 uncertainty / anxiety → assessed
 → offer to contact → wouldn't feel able to → perhaps felt nervous
 → wait results not able to share
 provides not meeting needs
 feels empty
 priority knowing if how dementia is impact of being diagnosed

**Appendix K: Individual Case Analysis – Example of Developing
Superordinate Themes (including quote extracts)**

“Eric”

Theme	Quote	Locator
1. What’s wrong with me? What’s happening to me?		
Noticing changes - Experiences that led to assessment – questioning self – making sense of changing self		
Noticing changes	<i>“well it had been over a period of time that err...I was...forgetting where I was going”</i>	Pg 1 : 4-5
Changing self	<i>“you know we’d go out somewhere and I’d know we should be going in a certain direction but err...but I didn’t know where I was going to go or...and I’d end up...and that went on for sometime...”</i>	Pg 1 : 9-12
Noticing changes	<i>“I’d be in there trying to grasp at words, you know, I...I’ve got a fairly large vocabulary but I couldn’t get it...kept missing...and couldn’t put over what I was trying to put over in a...a proper manner really, so it was...and I kept forgetting things you know just crazy really”</i>	Pg 1-2: 12-16
Questioning self		
Noticing difficulties	<i>“my memory was that bad, that when people were telling me things I wasn’t registering...”</i>	Pg 3: 50-52
Seeking answers – to understanding changing self		
Sought assessment	<i>“so I saw my GP and he referred me to here”</i>	Pg 2: 16-17
Theme	Quote	Locator
2. Being assessed		
Testing experience – mixed emotions		
Stressful experience	<i>“I came and it was a bit fraught because they give these bits of paper to do things on and you are sort of thinking...well you know when you come out...”that was wrong I didn’t do that right”, or and you know you feel</i>	Pg 2 : 17-21

Intense experience	<i>really quite concerned</i>	Pg 4: 55-59
Stressful experience	<i>“they had a crib list...but that’s no help to the patient...because they won’t answer your questions...you can’t ask questions while you’re doing it”</i>	
Stressful/confusing experience	<i>“I felt quite fraught when I went out of that one and that one...I felt awful, I sat there and I just couldn’t do the lot of it you know, I kept thinking you know “what’s this all about?” “that isn’t good”</i>	Pg 4: 65-68
Feeling helpless		
Extremely stressful	<i>“the third one...I was on my knees and I said to my wife “that was absolute s***...I feel ABSOLUTELY awful”, and I said “it was horrendous”, it just felt like nothing went right at all, you know”</i>	Pg 5 :73-76
Assessment process stressful		
Trying to justify process	<i>“[psychologist] was reading stories and then saying “memorise them and then repeat them back” and then...the stor...and then at the end of it...asking the same story again after going through three other stories, you know...and I was so confused...I know that’s probably the best way for you to...assess people but (sighs) it doesn’t help people, you know...it makes you feel rotten, you know...[psychologist] was nice really nice...you know...I really did like [psychologist]...and thought well you know...but I felt extremely stressed...when I went out from it and I got home”</i>	Pg 5: 76-84
Tests confusing	<i>“there were things like putting dice together in different pictures, it’s daft to me, you know, I used to think oh cripe I can’t being doing with it, you know, where as research into the first world war...I sit and read forever more...and err...that to me is err...you know and it stays in the memory funny enough...but THAT STUFF...just you know...”</i>	Pg 6-7: 105-112
Demanding experience		
Trying to make sense of performance	<i>“”DRAW THIS PICTURE” with all the line and the circles and the triangles, and then take it away and then do it again without the picture, you know, you just...(pause)...you just (sighs) CAN’T REMEMBER...”</i>	Pg 7: 111-114
Impossible task		Pg 8: 133-135

Felt incapable Feeling alone Isolating process	<i>"I'm thinking "this is..." you know "this is rubbish really", you know it...it's not registering with me what I'm supposed to do..."</i> <i>"you then are all off a sudden...all of a sudden you are alone...you know, and you're on your own and you've got no support and nothing, you just...(pause)...you've gotta go through it yourself"</i>	Pg 18: 299-302
"How am I doing?" – Monitoring / appraising performance		
Appraising performance Emotionally distressed	<i>"they give these bits of paper to do things on and you are sort of thinking...well you know when you come out..."that was wrong I didn't do that right", or and you know you feel really quite concerned"</i>	Pg 2 : 18-21
Experience informing appraisal of performance	<i>"at the time...it was bad...bad...li...like...it meant I DID have something...have some something wrong with my memory...it was going bad...I didn't like it..."</i>	Pg 7: 122-124
Appraising experience and performance / outcome	<i>"well with the memory loss and everything I wasn't sure, but really, you know, in the back of my mind, I suppose...I suppose (pause) it was that you know I've got, you know my mother-in-law, which I didn't want, you know that it would be, they would tell me that I've got <u>dementia</u> (said quietly)"</i>	Pg 10: 170-174
Getting through (coping) holding it together		
Trying not to think	<i>"I mean I tried to really clear my mind about it...tried not to think...but that's difficult isn't it, you know, it's...lots of things keep coming back to you...of life you know"</i>	Pg 13: 220-223
Fighting it - thoughts Turmoil in doubting self – experience of self	<i>"you have to fight it really...and well it's like...well you know it's right because you are experiencing it, you try, and you're thinking well it might not be because...DO I UNDERSTAND you know..."</i>	Pg 9: 146-149
Results important – focusing on outcome	<i>"and I wanted to find out really...I wanted to find out if there was anything"</i>	Pg 18: 314-315

Anxiously waiting for results: Waiting not knowing		
Waiting – uncertainty Questioning	<i>“you’ve got the review time, haven’t you...waiting for the results to be brought to you...that...that was the worst, you know...the waiting “what this...what that...” I dunno really, you...so yeah that WAS FRAUGHT...cos...you are questioning everything...going back “it was bad”...but then...mmmm (pause)...”</i>	Pg 11: 182-186
Waiting unknowing, worrying Imagining self as others	<i>“so it was a long period of time...and you are thinking “oh am I going...”, and of course the worst thing for me was my mother-in-law...who’s got...(pause)...<u>dementia</u> (said very quietly), she was in a home”</i>	Pg 14: 237-240
Waiting increasing anxiety – wondering about self, contemplating the worst	<i>“the stress becomes...greater because you worry more and more about, you know...the fact that...because you don’t know...” AM I going to be alright, is it...” you know what I mean...you’re really frightened...”</i>	Pg 15-16: 265-268

Theme	Quote	Locator
3. Focus on relationships with professionals (different approaches) Changing role within assessment		
Clinician welcoming/warm		
Conflict clinician role and process	<i>“[psychologist] was nice really nice...you know...I really did like [psychologist]...and thought well you know...but I felt extremely stressed...when I went out from it and I got home”</i>	Pg 5: 81-84
Clinician process focused (during assessment) – demanding absence of feedback, unbalanced directive		
Demanding – not helping	<i>“they had a crib list...but that’s no help to the patient...because they won’t answer your questions...you can’t ask questions while you’re doing it...”</i>	Pg 4: 56-58
Conflict clinician and process	<i>“[psychologist] was reading stories and then saying “memorise them and then repeat them back” and then...the stor...and then at the end of it...asking the same story again after going through three other stories, you know...and I was so confused...I know that’s probably the best way for you to...assess</i>	Pg 5: 76-84

Can't ask questions	<i>people but (sighs) it doesn't help people, you know...it makes you feel rotten, you know...[psychologist] was nice really nice...you know...I really did like [psychologist]...and thought well you know...but I felt extremely stressed...when I went out from it and I got home"</i>	
Not sure of alternative	<i>"normally you see...you can ask questions...but you can't in this...in this one...you then are all off a sudden...all of a sudden you are alone...you know, and you're on your own and you've got no support and nothing, you just...(pause)...you've gotta go through it yourself"</i>	Pg 17-18: 299-303
Conflicting role with clinician	<i>"but I don't know what you can do, that's the trouble...WHAT CAN YOU DO, you can't...lead anybody though cos then you won't get a proper understanding so erm...I don't know...(pause)"</i>	Pg 18: 308-311
	<i>""I mean I've got no complaint with it, what [psychologist] was like, you know [psychologist] was really nice and that...took time to listen...you know, get to know me...but then...different...it was different doing it, you know it...it's stressful you know...like I said...you're on your own then...then THEY CAN'T help and well...the last one I got in hell of a mess and when I got home...I was so depressed"</i>	Pg 19-20: 331-337
Withholding information		
Justifying clinician secrecy Stressful –not inclusive One way process	<i>"I know there's...know there's...understand that you know...that there has to be...blanked out or whatever because it's no good telling you it...it doesn't matter or whatever cos...IT MATTERS even for you to read about....well but that doesn't help the patient because you just sit there"</i>	Pg 4-5: 68-72

Theme	Quote	Locator
4. Finding out - Searching for meaning – making sense of changing self		
Getting answers (trying to make sense of self)– trying to understand – still confused ?incongruent with self experience		
Getting answers Still confused	<i>“I really felt that...I’d done something wrong, you know, that it was gonna be bad...BAD news, you know, but now they tell me there isn’t...seems impossible really, but I guess...I guess it is...must be right...”</i>	Pg 6: 92-96
Uncertainty of self still remaining after getting results	<i>“the answer was...they said that...I don’t have you know...<u>dementia</u> (said quietly), but then...you know do they really know...like it’s not always certain is it...and well like I DID forget my appointment, “not like me” so.....”</i>	Pg 11-12: 195-198
Results feel meaningless Incongruent self	<i>“I got average or above average so...yeah but you know it...it’s no help when it comes as such really because you’ve been stressed out for that long worrying about it that when you’re told its ok, it means nothing”</i>	Pg 21: 362-366
Still feel uncertain – some element of doubt – due to own experience of self		
Incongruent self Confused problems still remain	<i>“I was in trouble on Monday as I was due to have a B12 injection and I still haven’t had it...and it’s the first time ever in my life I’ve missed a medical appointment...never... ever done it before and erm...that concerned me a little bit as I’d missed that”</i>	Pg 6: 95-99
Impact of current self view Stopped doing certain things Feeling incapable	<i>“I felt like well I think it’s all the pressure that built up over the assessment, you know...I...I...err doubted myself, you know...<u>not sure if I can still do it</u> (said quietly)...”</i>	Pg 13: 213-215
Still some uncertainty	<i>”COULD there have been anything wrong”, you know, and I suppose I still don’t REALLY know”</i>	Pg 18-19: 316-317

Trying to move on – trying to manage uncertainty		
Positive self talk – uncertainty still remains	<i>“and I have to keep reminding myself that, you know that there isn’t anything there, it’s not showing but err...I dunno know...I dunno, things just keep...you know my memory’s still bad, so...(sighs)”</i>	Pg 21: 365-368

Appendix L: Cross Case Analysis – Master List of Group Themes derived from Individual Case Themes

1. “Things aren’t right, what’s wrong with me”	2. “Testing by name, testing by nature”
<p><u>Noticing changes: questioning self</u></p> <p>“Jean” – noticing changes, feeling different, questioning self “David” – noticing changes, altered sense of self “Derek” – noticing difficulties, wondering why “Mick” – noticing difficulties, questioning sanity “Eric” – noticing difficulties/changing self “Terry” – feeling different/noticing difficulties “Janet” – noticing changes, concerned about self “Zeena” – awareness of difficulties questioning why/self</p>	<p><u>Emotional rollercoaster: trying to make sense of it all</u></p> <p>“Jean” – testing experience, mixed emotions (enjoyment vs frustration) “David” – mixed emotions, highs and lows “Derek” – difficult experience, taken by surprise, mixture of emotions “Mick” – testing experience, emotionless “Eric” – stressful experience, emotionally intense “Terry” – intensely emotional “testing” experience “Janet” – “testing” experience, stressful/distressing “Zeena” – testing emotional experience, feeling unprepared</p>
<p><u>Needing to know: seeking answers</u></p> <p>“Jean” – wanting to make sense of difficulties “David” – seeking answers, wanting to disprove fears “Derek” – wanting to understand problems “Mick” – seeking answers about problems “Eric” – seeking answers from professionals “Terry” – wanting answers, to understand difficulties “Janet” – wanting answers/resolve fears, understand problems “Zeena” – wanting answers, not feeling listened to</p>	<p><u>Getting through</u></p> <p>“Jean” – ways of coping, moving past it “David” – getting through, getting on with it “Derek” – coping to manage distress “Mick” – holding it together, getting through “Eric” – getting to the end, holding it together “Terry” – coping with it all “Janet” – holding it together, getting through “Zeena” – coping with assessment</p> <p><u>Tell me how I’m doing: making assumptions</u></p> <p>“Jean” – wanting to know how doing “David” – monitoring performance, jumping to conclusions “Derek” – wondering about performance, wanting answers “Mick” – questioning performance, wanting answers “Eric” – wondering about/appraising performance “Terry” – How am I doing?, wanting to know, making assumptions</p>

	<p>“Janet” – monitoring performance, needing to know</p> <p>“Zeena” – what’s going on, how am I doing?</p>
3. Professional roles: different side of the same coin	4. Finding out...
<p><u>Seeing the person: being involved</u></p> <p>“Jean” – professional as welcoming, person-focussed, feeling valued</p> <p>“David” – professional as involving, person-centred</p> <p>“Derek” – professional taking time, person-focused, feeling involved</p> <p>“Mick” – professional collaborative, feeling valued</p> <p>“Eric” – professional welcoming and warm</p> <p>“Terry” – feeling human, feeling valued</p> <p>“Janet” – person-centred and collaborative relationship</p> <p>“Zeena” – non-judging, welcoming, person-centred relationship</p>	<p><u>Being told, mixed emotions, mixed responses</u></p> <p>“Jean” – getting results, mixed emotions</p> <p>“David” – being told, mixed emotions</p> <p>“Derek” – getting answers, end to uncertainty</p> <p>“Mick” – getting answer, resolving fears</p> <p>“Eric” – getting answers, feeling confused</p> <p>“Terry” – being told, confirming fears</p> <p>“Janet” – not getting answers, uncertainty remains</p> <p>“Zeena” – not getting answers, feeling confused</p>
<p><u>Sidelining the person: lost in the process</u></p> <p>“Jean” – professional as task-focused, feeling judged</p> <p>“Derek” – professional as powerful/secretive, feeling excluded</p> <p>“Eric” – professional process focused</p> <p>“Terry” – feeling dehumanised and dismissed</p> <p>“Janet” – professional in role of power, feeling sidelined</p> <p>“Zeena” – process-focused role, disconnected relationship</p>	<p><u>Trying to adjust and move on</u></p> <p>“Jean” – looking ahead, trying to remain hopeful</p> <p>“David” – moving on, balancing hope with acceptance</p> <p>“Derek” – moving on, accepting of difficulties</p> <p>“Mick” – feeling reassured, moving on</p> <p>“Eric” – unresolved uncertainty, mistrusting of outcome</p> <p>“Terry” – taking back control, planning ahead</p> <p>“Janet” – acceptance as moving on, uncertainty remains</p> <p>“Zeena” – wanting to move on, uncertainty remains</p>

Appendix M: Presence of Themes Within Participants' Accounts

Theme	Jean	Zeena	Terry	Derek	David	Mick	Janet	Eric
1. Noticing changes	X	X	X	X	X	X	X	X
1. Seeking answers	X	X	X	X	X	X	X	X
2. Emotional rollercoaster	X	X	X	X	X	X	X	X
2. Getting through	X	X	X	X	X	X	X	X
2. Tell me how I'm doing	X	X	X	X	X	X	X	X
3. Seeing the person	X	X	X	X	X	X	X	X
3. Sidelining the person	X	X	X	X	-	-	X	X
4. Getting results	X	X	X	X	X	X	X	X
4. Trying to move on	X	X	X	X	X	X	X	X