A qualitative study exploring psychological therapists' experiences of working psychotherapeutically with individuals diagnosed with dementia

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1.0 Abstract

In the past it was assumed that psychotherapy with the dementia population was not possible. There currently exists a growing evidence base for the use of a variety of psychotherapeutic models with individuals diagnosed with dementia. Less research, however, has focused on the actual subjective experiences of psychotherapy or the therapeutic process, including the therapeutic relationship. The current qualitative study therefore aimed to gain an in depth understanding of the subjective experiences of psychological therapists working psychotherapeutically with individuals diagnosed with dementia including experiences of the therapeutic process and relationship. Semi-structured interviews were carried out with nine psychological therapists regarding their experiences of working psychotherapeutically with individuals diagnosed with Alzheimer's disease. Verbatim transcripts were analysed using Interpretative Phenomenological Analysis which resulted in the generation of three super-ordinate themes: Considering the Psychotherapeutic Work; Bridging between Two Worlds; and The Detrimental Effect of Dementia on the Therapist and the Therapeutic Work. These super-ordinate themes along with sub-themes are expanded into a narrative account of participants' experiences. Of particular interest, the concept of identity arose from the narratives. Dementia was conceived to act as a threat to participants' sense of identity preventing them from sustaining their usual roles or preserving their existence as therapists. This finding and additional results from the analysis were considered in light of existing theory. The implications of the findings for clinical practice, service provision and training were highlighted. Limitations of the current research study were outlined and recommendations were put forward for future research.

2.0 Introduction

2.1 Overview

This literature review will outline contextual and theoretical issues regarding individuals with dementia. Dementia will be defined and placed within a historical and political context and traditional approaches to treatment will be critically reviewed. Psychotherapy will subsequently be considered in the context of dementia and current literature surrounding individual psychotherapeutic models will be critically analysed. The experiences of psychological therapists in working with individuals with dementia will be examined including consideration of therapeutic processes such as the therapeutic relationship. Finally, a rationale for the current research study will be discussed and the research questions will be outlined. The review will be considered throughout from a counselling psychology perspective.

The following section aims to provide the reader with a brief introduction to counselling psychology and dementia in order to place this study in context. Firstly the main philosophical principles of counselling psychology will be outlined. Dementia will then be defined and significant aspects relating to the condition will be described. Finally, the historical, social and political position of dementia will be delineated in this section.

2.1.1 Key Definitions / Characteristics

Counselling psychology has been defined in this research study according to the definition laid out in the British Psychological Society (BPS: 2005) Division of Counselling Psychology professional practice guidelines. Counselling psychology is an applied professional psychology strongly influenced by the humanistic tradition drawing on phenomenological models as well as scientific research. The therapeutic relationship is central to the profession in which subjective engagement, empowerment and validation of the individual in their own right are highly valued concepts.

The following definitions of dementia, defined in the United Kingdom (UK) according to the International Classification of Diseases 10 (WHO: World Health Organisation, 1992; ICD-10) and the Diagnostic and Statistical Manual of Mental Disorders 4th Edition (APA: American Psychiatric Association, 1994; DSM-IV), have been employed in this research study. As outlined by Henderson and Jorm (2002), dementia (also termed *senile infirm*, *senile confused* or *elderly mentally infirm*) characterised by its sudden onset, is defined as slow but continuous deterioration in functioning across a number of different areas. Impairment is evident both in long and short term memory consequently interfering with the functioning of everyday activities. The ability to think, plan and make judgements can additionally be impaired along with disturbances of higher cortical functioning, such as, executive functioning and personality change. A decline in emotional control, motivation and social interaction is also apparent in dementia. These symptoms can be understood in terms of structural and chemical changes within the brain which accelerate cell death and impair functioning of remaining cells as a result of physical diseases such as Alzheimer's disease, Vascular dementia, dementia with Lewy bodies and Frontal lobe dementia described below (McKeith & Fairbairn, 2001).

2.1.1.1 *Alzheimer's disease*

Named after a German physician, Alois Alzheimer, in 1907, Alzheimer's disease is the most common form of dementia (Thompson, 1997). Due to neuronal loss initially in the medial temporal lobe and hippocampus, the predominant symptom in Alzheimer's disease is memory impairment. Impairment commonly also occurs in language skills, visuospatial abilities and in activities of daily living associated with the parietal lobes. Additionally, frontal lobe damage can lead to personality and behavioural changes, impaired social judgement and lack of insight (McKeith & Fairbairn, 2001). Thompson (1997) highlighted a stage model of change describing key characteristics common to the Alzheimer's disease process. During an initial *forgetfulness* phase individuals display difficulties in recalling recent events, people, places and objects. Additionally, a lack of concentration, disorientation and abstract thinking is common to this phase. Individuals may also feel anxious or irritable, experience denial and fear when faced with new or unexpected events. The second *confusional* phase, in addition to continued memory impairment, is associated with a decline in intellectual functioning such as attention, word-finding difficulty and in occupational skills. During the final phase, the *dementia* phase, an individual's behaviour may appear disjointed and they may require assistance with self-care. Ultimately this phase may lead to complete deterioration in language, memory and physical skills. This process is reported to develop over a number of years. It should be noted, however, that stage models such as the one described above, have been criticised for being constructed within a general biomedical model (Bender & Cheston, 1997), and as such do not account for an individual case.

2.1.1.2 *Vascular dementia*

This form of dementia is caused by problems in the supply of blood to the brain leading to impairment in areas of the brain related to, for example, memory, intelligence, language or visuospatial abilities (Henderson & Jorm, 2002). The onset of symptoms may be sudden and focal in presentation or may be a stepwise deterioration featuring a number of smaller strokes or transient ischemic attacks (McKeith & Fairbairn, 2001). Vascular dementia is usually diagnosed if an individual is demonstrating impairment in certain areas of cognitive functioning, whilst other areas remain relatively intact, and where there is clinical evidence of brain damage and cerebrovascular disease (Henderson & Jorm, 2002).

2.1.1.3 Dementia with Lewy bodies

A more recent addition to the dementias, dementia with Lewy bodies is characterised by fluctuating cognitive impairment with episodes of confusion, including psychotic episodes, amongst periods of clarity. The disease progresses gradually with continuing cognitive impairment. Three main features can be identified in dementia with Lewy bodies. Firstly, deficits in attention are apparent where attention may fluctuate rapidly. Individuals experience persistent visual hallucinations, such as visualising animals or people. Finally impaired movement is evident characteristic of Parkinson's disease which includes slowness of movement, muscle rigidity and tremor (McKeith & Fairbairn, 2001).

2.1.1.4 *Frontal lobe dementia*

Also degenerative in nature, frontal lobe dementia is a less common form of dementia in which neurones are lost from the frontal and temporal lobes. Where loss occurs in the frontal lobes, personality change can be observed in individuals. This may include; apathy, inertia or over-activity, disinhibition, poor social judgement and recklessness. Where the temporal lobe is affected, impairment in language skills can be observed in addition to impaired understanding of the meaning of verbal or visual information. In comparison to Alzheimer's disease, memory skills and other cognitive features often remain intact for much longer. Frontal lobe dementia is more common in younger people (McKeith & Fairbairn, 2001).

2.1.1.5 *Other dementias*

A full description of other forms of dementia is beyond the scope of this literature review, however, they include; mixed dementia, alcohol related dementia, dementia due to Aids, Creutzfeldt-Jacob disease and Huntington's disease (See DSM-IV, APA, 1994).

2.1.2 Epidemiology

Dementia can affect individuals at any age but is more common in individuals over the age of 65 years. The Alzheimer's Society (2007) has highlighted the fact that one in 14 people over the age of 65 years have some form of dementia and that the rate increases to one in six people over the age of 80 years old. Internationally, dementia has been identified in all countries, cultures, races and genders in which research has been completed and it has been estimated that 24.3 million people worldwide have dementia. Moreover, an estimated 4.6 million new cases appear every day reaching a projected 81.1 million by 2040 (Alzheimer's Society, 2007).

Within the UK it has recently been estimated that there are 821,884 individuals diagnosed with dementia which equates to 1.3% of the UK's population (Luengo-Fernandez, Leal & Gray, 2010). It is predicted that by 2021 there will be approximately 940,000 individuals diagnosed with dementia and the figure is anticipated to rise by 154% over the next 45 years. This rise is thought to be largely due to the ageing population in which older individuals are most at risk of developing dementia (Alzheimer's Society, 2007). Alzheimer's disease has been estimated to be the most common form of dementia within the UK with 62% prevalence and is also more common in women. Mortality rates for the UK related to dementia, although difficult to calculate due to co-morbidity, are estimated to be 10% of deaths in men and 15% in women over the age of 65 years old. Although there is much individual variability it is thought that dementia may shorten an individual's life considerably (Alzheimer's Society, 2007). Additionally, dementia is estimated to cost the UK economy £23 billion per year in health and social care which is more than cancer and heart disease combined (Luengo-Fernandez, Leal & Gray, 2010). Given this large estimated rise in the dementia population, it is likely that individuals diagnosed with dementia will be increasingly present in older adult psychology services in which counselling psychologists might work. Consequently, research studies, such as this one, will be invaluable in informing counselling psychologists in regards to psychotherapeutic work with individuals with dementia.

2.1.3 Diagnosis

Symptoms of dementia such as changes in cognition or emotion are usually initially recognised by the individual, a close relative, friend or by the individual's general practitioner (GP). Recognition of dementia can be challenging and prolonged, often relying on collecting evidence from a variety of sources, including the individual, their family and other professionals. The process may be hindered by denial from both the individual diagnosed and their family, and limited awareness of symptoms, or inadequate diagnostic skills on the part of the professional involved (NICE: National Institute for Health and Clinical Excellence, 2006). Diagnosis can occur within primary services and increasingly within secondary care memory clinic services and is usually based upon self-report of symptoms, informant histories, measurement of cognitive loss using standardised measurement, exclusion of other diagnoses such as depression, delirium or urinary tract infection and brain scanning (NICE, 2006). Due to the high incidence of dementia, cases are screened and prioritised considerably. For many individuals, it is not possible to diagnose dementia outright and assessment may need to continue over a period of one year to observe any deterioration that may be occurring. In recent years it has become more common to inform an individual about their diagnosis. This can provide a further challenge for professionals where there are issues for the individual with lack of insight or where relatives are opposed to disclosure (McKeith & Fairbairn, 2001). Frequently, individuals with dementia are under-diagnosed and often when the diagnosis is made, it is too late for the individual to make decisions on appropriate treatment options or care due to capacity issues or because they have reached crisis point and more immediate intervention is required (Department of Health, 2009). A further complication in the diagnosis of dementia can be the difficulty of differentiating between depression, delirium and dementia as all three conditions can present in the form of confusion (McKeith & Fairbairn, 2001). The therapeutic relationship has been observed to be important within the diagnostic process (Cheston & Bender, 1999) as well as counselling skills (Goudie, 2003).

Consequently, psychological therapists, such as counselling psychologists coming from a philosophy in which the therapeutic relationship and the subjective experience of the individual are held in high esteem (BPS, 2005), are well placed to provide support surrounding the diagnostic process.

2.1.4 Risk / Protective Factors

Henderson and Jorm (2002) proposed four main risk factors for dementia which are supported by considerable evidence. They also highlighted however that there are many other risk factors which are more uncertain. Loosely divided into genetic and environmental factors, some risk factors are more pertinent to particular sub-types of dementia than others.

2.1.4.1 *Genetic risk factors*

A family history of Alzheimer's disease or Vascular dementia is associated with an increased risk of developing the disease for siblings or children (NICE, 2006). Some evidence suggests that the risk to relatives is dependent upon the age at which the initial case developed. Where an individual developed the disease at a younger age, such as aged 40 or 50 years old, a relative is at greater risk of developing the disease compared to those developing the disease in their 80's (Henderson & Jorm, 2002). Individuals diagnosed with Down's syndrome, a genetic disorder resulting from chromosomal abnormality, are also at increased risk of developing dementia compared to the general population (Rabe, Wisniewski, Schupf, et al., 1990). Specific genes, such as Apolipoprotein E, have also now been identified as related to some cases of Alzheimer's disease (Henderson & Jorm, 2002).

2.1.4.2 *Environmental risk factors*

One significant environmental risk factor is age. The risk of developing dementia increases with age although it is questioned whether age itself is the risk factor or whether with age other factors are increasingly likely to influence an individual's development of dementia (NICE, 2006). Smoking, high blood pressure and diabetes have all been identified as risk factors for Alzheimer's disease and Vascular dementia. These factors also increase the likelihood of stroke which predisposes an individual to dementia (NICE, 2006). Cooper and Holmes (1998) also identified an increased risk of developing dementia with a past history of psychiatric problems, schizophrenia and depression. Other risk factors currently suggested, although with limited evidence, include; head trauma, occupational exposure to solvents, lead or aluminium and ethnic background (Henderson & Jorm, 2002).

2.1.4.3 *Protective factors*

There is evidence that is indicative of several protective factors for dementia thus reducing the risk of the disease. Such protective factors include taking anti-inflammatory drugs predominantly used to treat inflammatory diseases and oestrogen replacement therapy (Henderson & Jorm, 2002). Higher education level and higher pre-morbid intelligence have also been associated with protection against dementia (Schmand, Smit, Geerlings & Lindeboom, 1997).

2.1.5 Historical / Political Position

In order to set the scene for this research study, the following section will examine the historical and political background of the dementia field. Pre-1930, older adults with physical or mental health issues were deemed to be outside the scope of medicine (Cantley, 2001). Up until 1960 many individuals with dementia, as with other individuals with mental health issues, remained in institutions and it was not until post 1960 that a move began towards community care (Cantley, 2001). Within the 1970's and 1980's the concept of 'home care' developed and much of the caring for individuals with dementia was carried out within the family network. At this time, the Alzheimer's Society was founded in order to advocate for individuals with dementia and their caregivers (Manthorpe & Adams, 2003). During the 1990's health and social care organisations focused on finding the right place to support individuals with dementia and there was a movement away from hospital care to private sector nursing home care. By the late 1990's, issues of incapacity in mental health were at the forefront of government policy and incapacity in dementia became a key focus, possibly to the detriment of other important areas in the field of dementia (Manthorpe & Adams, 2003). In 2001, the National Service Framework for older people was published which established a set of national standards in the form of a ten year plan for service development (Department of Health, 2001). Of significance, the framework emphasised the importance of early recognition, diagnosis and treatment in dementia. Since this time, the framework has been followed up with a number of government papers (for example, Department of Health, 2003; Department of Health, 2006) which focused on the progress in achieving the standards laid out in the original government paper. Alongside this, the Social Care Institute for Excellence (SCIE) and NICE, commissioned guidelines for professionals in health and social care in supporting people with dementia and their caregivers (NICE, 2006). Finally, most recently in 2009, a national dementia strategy was published due to failures in the current provision of dementia services, aiming to ensure that significant improvements are made to dementia services across three main areas: improved awareness, earlier diagnosis and intervention and a higher quality of care (Department of Health, 2009).

Alongside the political picture, which Manthorpe and Adams (2003) considered to be as complex as dementia itself, dementia has also been constructed socially in different ways over time. Initially, dementia was constructed within a biomedical model in which the focus was predominantly on brain changes and cognitive functioning, encouraged by the advancement of technology at this time. Subsequently, the psychosocial features of dementia were minimised and the disease was very much placed within the individual (Adams & Bartlett, 2003). Within the psychological field, dementia was initially constructed in relation to the behavioural aspects of the disease and, in doing so behaviour was viewed to be a challenging feature of dementia, thus failing to consider the subjective experience of the individual (Adams & Bartlett, 2003). More recently, researchers such as Kitwood (1990; 1997) have been prominent in challenging the biomedical model and encouraging a shift towards a psychosocial model of dementia leading to a more person-centred approach to dementia care. Kitwood (1997) recognised that the personhood of individuals with dementia remains together throughout dementia but that the individual becomes caught in a spiral that challenges their sense of self. Underlying this process, Kitwood (1990) identified social processes such as disempowerment, infantilisation, stigmatisation or invalidation which work to undermine individuals with dementia and thus contribute to their decline. Whilst Kitwood's ideas have been significant in the dementia field, much of the work was anecdotal with little empirical support (Adams & Bartlett, 2003). Consequently, there has been a wealth of literature exploring the subjective experiences of individuals with dementia (for example, Clare, 2003; Gillies, 2000; Keady, Nolan & Gilliard, 1995; Pearce, Clare & Pistrang, 2002). These changes in the way dementia is socially constructed in addition to the political changes outlined above have led to an expansion in the scope of mental health services and treatments provided. Moving away from a positivist position and towards a more humanistic perspective in which the subjective experience is significant, there seems to be strong resonance between how the dementia field has developed and the values and philosophy of counselling psychology. Thus it could be perceived that counselling psychologists are in an excellent position to make a valuable contribution to the dementia field at this time. Furthermore, given the recent political focus, particularly with the development of the national dementia strategy (Department of Health, 2009), this research study appears aptly timed and will be able to make an important contribution to the ongoing development in the field currently at the forefront of the political agenda.

2.1.6 Additional Needs

It is rare that an individual will present with one single diagnosis such as dementia and frequently individuals will have additional mental or physical issues which can provide further complications (McKeith & Fairbairn, 2001). Depression, for example, appears to be more frequent in dementia populations than in the general or aged population (Scholey & Woods, 2003). Ballard, Bannister and Oyebode (1996) established in their literature review that, amongst clinical samples, the incidence of depression and dementia concurrently was approximately 20% thus causing considerable excess disability for these individuals. Anxiety is also common in people with dementia (Qazi, Shankar & Orrell, 2003). Furthermore, following dementia onset, early traumatic memories can become reactivated or trauma can be experienced following difficulties coping with the dementia experience (Stokes & Goudie, 2002). The picture of dementia can also be complicated by additional needs such as being diagnosed with a learning disability or being diagnosed at a younger age with dementia. Additionally, where individuals diagnosed are from an ethnic minority background, there may be challenges for clinicians in understanding cultural expectations and overcoming language barriers (McKeith & Fairbairn, 2001). Given these complexities, psychological therapists such as counselling psychologists who work with a range of client presentations often in challenging settings (Orlans & Van Scoyoc, 2009) are well situated to provide support for individuals with dementia.

2.2 Therapeutic Interventions

The following section provides a summary of pharmacological and non-pharmacological interventions currently available as alternatives to psychotherapy in the treatment of dementia.

2.2.1 Pharmacological Interventions

Whilst no drug treatments can currently provide a cure for dementia, drugs have been identified that can assist in slowing down the progression of the disease and improve symptoms. In 2001, NICE approved the prescription of acetylcholinesterase inhibitor medication (donepezil, galantamine, rivastigmine) to individuals with mild to moderate Alzheimer's disease (Royan, 2003). A further drug, memantine, has also been licensed to treat moderate to severe Alzheimer's disease. Rivastigmine is the only drug licensed to treat other forms of dementia such as Vascular dementia or dementia with Lewy bodies (NICE, 2006). The effectiveness of these drugs has been established in a series of clinical randomised control trials (Burns & O'Brien, 2006). Apart from acetylcholinesterase inhibitors, other drugs, such as ginkgo biloba, antioxidants vitamin E and B^{12} and anti-inflammatory drugs have also been identified in the pharmacological treatment of dementia (NICE, 2006). According to Burns and O'Brien (2006), the British Association for Psychopharmacology have confirmed that there is some evidence to suggest that ginkgo biloba may have certain benefit on the cognitive functioning of individuals with dementia. In contrast, there are no positive effects currently for antioxidants or anti-inflammatory medication when their side effects are taken into consideration. In addition to the quantitative evidence for the effectiveness of pharmacological treatments, such as acetylcholinesterase inhibitors, there is also some qualitative evidence to support the positive effects of these drugs. Reports from clinical practice suggest that the drugs have been found to improve mood and motivation and enhance daily living skills and general quality of life for individuals with dementia (Royan, 2003). Bayer (1994), in a qualitative study exploring caregivers' opinions of dementia drugs, established that caregivers valued them particularly in the earlier stages of the disease. More recently, Hutchings et al. (2010) explored the lived experience of 12 individuals with Alzheimer's disease who were taking dementia medication and found a mixed response to the treatment. Given the advancement in pharmacological interventions in the treatment of dementia, it is likely that individuals with dementia will remain cognitively intact for longer and as a result may present to older age services with psychological difficulties more frequently. Thus it is anticipated that the role of a psychological therapist, including counselling psychologists, within these services will become more prominent. Therefore it will become increasingly important to develop research surrounding psychotherapeutic work in the dementia field.

2.2.2 Non-pharmacological Interventions

2.2.2.1 Complementary and alternative medicines

The Alzheimer's Society (2009) highlighted a number of complementary treatments shown to be useful for individuals with dementia. Such treatments include: herbal medicine, aromatherapy and massage, acupuncture, dietary supplements, melatonin and bright light therapy and multi-sensory stimulation. Whilst there is no substantial evidence in support of these treatments currently, there have been some significant initial findings suggesting further research is warranted.

2.2.2.2 Cognitive focused interventions

A number of interventions exist which focus on improving or maintaining cognitive functioning in individuals with dementia. Cognitive stimulation, for example, centres on guided practice of regular activities with the assumption that repeated practice of these tasks will lead to an improvement or at least maintenance in the level of functioning for the task involved. These tasks can be carried out either in a group or individual setting usually over a short duration such as 14 sessions. The value of a cognitive stimulation approach has been established in a number of studies (See Spector & Orrell, 2006, for an overview). Spector et al. (2003), for example, evaluated the effects of cognitive stimulation therapy groups on cognition and quality of life for individuals with dementia in a single-blind, multi-centre, randomised controlled trial. Significant improvements were established in the 115 individuals in the intervention group compared to 86 controls on a number of measures of cognitive functioning and quality of life. Most significantly, the results were comparable to trials of drug treatments for dementia. One of the main limitations for the study, as with other randomised controlled trials, was its narrow inclusion criteria making it difficult to generalise to the wider clinical population. The study excluded day centres and residential units, in which there were less than eight people available to participate, and also excluded individuals with sensory impairments or communication difficulties. It is likely that, in a clinical situation, services will be supporting a mixture of presentations and numbers of individuals so are less likely to make exclusions from groups given the typically limited resources available to them. Additionally, it appeared that evaluation of the effectiveness of the group focused only on those individuals in the milder stages of dementia and not the later stages. Finally, the researchers acknowledged that, to maintain benefits, the group would have to continue beyond the evaluated 14 week programme. As part of this randomised controlled trial, Knapp et al. (2006) completed a cost-effectiveness analysis of the therapy. They identified that it was no more costly than care as usual, which consisted of brief activities or doing nothing, but that cognitive outcomes and quality of life improved significantly. In addition to the limitations outlined above, a further criticism of this study is that cost-effectiveness appeared to have been measured over a relatively short period and, consequently, further analysis would be needed over time to demonstrate that cost-effectiveness is maintained.

In contrast, cognitive rehabilitation is a more person-centred approach in which professionals work collaboratively with the individual and their family in setting individual goals and providing techniques for individuals with the aim of improving the everyday functioning of those individuals (Clare & Woods, 2001). In a recently updated Cochrane Review of cognitive interventions in which nine research studies were identified, Clare and Woods (2009) established limited results for the efficacy of cognitive interventions in general, and found insufficient evidence to appraise the cognitive rehabilitation approach. However, the researchers reported methodological limitations of the studies reviewed which they suggested may have hindered the possibility of displaying significantly positive results. In particular, there was considerable variability in the outcome measures employed in the studies and the sample sizes were reported to be small (Clare & Woods, 2009). It was emphasised that whilst there is currently a lack of randomised controlled trials focused on individual cognitive rehabilitation there are some positive results for single case experimental designs and group studies. It is therefore apparent that further research is required to support the cognitive rehabilitation approach in dementia work.

Reminiscence work involves discussing and remembering past experiences or memories through the use of external aids, such as old pictures, objects, music and life story books (Brooker, 2001). Reminiscence can be traced back to the earlier concept of life review in which individuals naturally reflect back upon their life experiences (Woods, Spector, Jones, Orrell & Davies, 2005). Woods et al. (2005), in a Cochrane review, investigated the effects of reminiscence therapy for individuals with dementia and their caregivers. Only four randomised controlled studies were identified as suitable for analysis. Out of the studies analysed, it was established that significant results were apparent a few weeks after the reminiscence work ended in terms of improvement in cognition, mood and functional ability. Caregivers also reported a significant reduction in strain following the work. However, a number of limitations came to light in these studies, largely in terms of the variation in content of the studies reviewed, and subsequently the researchers acknowledged that the results should be treated with caution. Given the small number of studies available on reminiscence therapy at the time of the review, it is difficult to draw any firm conclusions and further research in the area would be valuable.

Given the existing research evidence for cognitive focused interventions, reviewed briefly here, it is apparent that cognitive stimulation therapy has demonstrated the most positive outcome, despite a number of methodological limitations in the studies. Corroborating with this, in the NICE guidelines for the treatment of individuals with mild to moderate dementia, cognitive stimulation has been recommended alongside drug treatments (NICE, 2006).

2.2.2.3 Other therapeutic interventions

Other therapeutic interventions delineated in the dementia literature include, dance movement therapy, in which individuals can express creativity and communicate feelings that might be difficult to express in other ways (see Violets-Gibson, 2004) and music therapy, which enables individuals with dementia to connect with the outside world and for others to meet the individual through the common ground of music (see Darnley-Smith, 2004). Although a relatively new and controversial approach, doll therapy is also cited in the dementia literature (see Minshull, 2009). Furthermore, art therapy has been evaluated as an approach to use with individuals with dementia

(Waller, 1999). Further evaluation of these approaches is beyond the scope of this literature review.

2.3 Psychotherapy for Individuals with Dementia

The following section aims to define psychotherapy and psychotherapeutic models and consider critically the existing evidence-base for these models in the context of dementia. Existing literature, regarding the experiences of psychotherapy from the perspective of professionals and individuals with dementia, will subsequently be critically examined.

2.3.1 Psychotherapy Definition

Psychotherapy, also referred to as 'talking therapy' is a way of alleviating psychological distress. It is used in the treatment of mental health and emotional needs in which an individual's well-being, work, relationships and other aspects of daily living are being greatly affected. In psychotherapeutic work, psychologists tend to understand an individual's psychological distress in terms of the way in which the individual experiences events in the context of their individual history and prior experience. Two factors have been identified as being relevant to the effectiveness of psychotherapy, firstly the individual's motivation for therapy, expectations and need to change, and secondly the therapeutic relationship (BPS, 2000-2009). Counselling psychologists can be seen to draw on a range of psychotherapeutic models in their practice (Woolfe, Dryden & Strawbridge, 2003) some of which will be outlined below in the context of dementia.

2.3.2 Historical and Current Perspectives

Until recently, the principal clinical perspective was that individual psychotherapy was not possible with those diagnosed with dementia due to the cognitive impairments associated with the disease (Bender & Cheston, 1997). Given the low perceived efficacy, the area received little theoretical or empirical interest (Jones, 1995). Instead, the focus of psychotherapeutic interventions was aimed towards the caregiver, assisting them in coping with the emotional impact of caring for an individual with dementia (Mosher-Ashley & Witkowski, 1999) or group therapy for individuals diagnosed with dementia focused on cognitive functioning (Jones, 1995). Where any individual psychotherapeutic interventions were carried out, these were of a behavioural nature, consistent with the view of dementia as a problem to be managed (Brierley et al., 2003). Gradually, as psychosocial constructions of dementia developed, a shift occurred from the stigmatised view of dementia as just an organic illness in which a loss of self occurs, to a view highlighting that individuals with dementia do want to communicate and make sense of their experiences (Kitwood, 1997). Additionally, as more recent advances in pharmacological treatments have occurred there appears to be more of a delay in cognitive decline enabling individuals to have greater insight into their difficulties for longer. As a consequence, greater insight may increase an individual's emotional distress therefore providing more opportunity for psychotherapeutic intervention (Brierley et al., 2003). These developments raise the possibility of engaging with individuals diagnosed with dementia on a psychotherapeutic basis, thus shifting away from the notion of dementia as a problem to be managed, and moving towards acceptance of the individual as a whole (Cheston, 1998). Consequently, there has been a wide expansion in the literature which examines psychotherapy with individuals with dementia to help them change psychotherapeutically or to provide emotional support (Bender & Cheston, 1997). Whilst much of the research evidence has been mainly anecdotal, in the last decade or so a strong evidence base has been established (Mosher-Ashley & Witkowski, 1999). There are now a wide variety of psychotherapeutic approaches highlighted by the literature as valuable in working with individuals with dementia on both an individual and group basis. These include cognitive behavioural, psychodynamic, narrative and humanistic models (Cheston, 1998). These approaches will be considered in more detail below. Importantly, it must be acknowledged that in addition to *doing psychotherapy* with individuals with dementia, the main focus of this section, emphasis can also be placed on *being psychotherapeutic* with individuals with dementia in a more informal context (Cheston, 1998).

2.3.3 Psychological Needs of Individuals with Dementia

In the extensive literature exploring the subjective experiences of individuals with dementia (such as, Clare, 2003; Gillies, 2000; Keady, Nolan & Gilliard, 1995; Pearce, Clare & Pistrang, 2002), a number of psychological needs of individuals diagnosed with dementia have been identified as particularly common, and therefore may play a key role in any psychotherapeutic encounter. The main theme running through many subjective accounts was that of a sense of loss which might include, for example, loss of intellectual ability, communication or independence. Ultimately this sense of loss may result in a loss of self-esteem which might impact upon the individual's ability to cope with their diagnosis and potentially result in secondary feelings of depression or anxiety (Bartlett & Cheston, 2003). A further common experience of individuals diagnosed with dementia is their struggle to preserve a sense of self (Holst & Hallberg, 2003). Similarly to other losses experienced, this struggle may lead to lowered self-esteem and depression. Consequently, it could be implied that addressing these themes of loss and associated feelings would be important in psychotherapy. A further need identified for individuals diagnosed with dementia is that of making adjustments and beginning a process of acceptance of the disease and its course. This can be a challenging experience for individuals involving a large amount of uncertainty, and sometimes denial, thus psychological support can be beneficial (Bartlett & Cheston, 2003). It has also been established in the literature that individuals with dementia utilise a wide range of coping strategies (for example, Dijkhuizen, Clare & Pearce, 2006; Pearce, Clare & Pistrang, 2002). Therefore the acknowledgment of existing coping techniques and the suggestion of other coping strategies may be an important part of the therapeutic provision (Bartlett & Cheston, 2003).

These qualitative studies are invaluable in providing a deep insight in to the subjective experience of individuals' experiences of dementia and demonstrate the value of qualitative research in the dementia field. Given their focus on the subjective experience, they also correspond well with the philosophy of counselling psychology in which the subjective experience of the individual is highly valued (BPS, 2005). However, given the nature of the qualitative paradigm, sample sizes tend to be small and this limits the extent to which they can be generalised to the wider dementia population. Nonetheless, taking this literature together, a number of themes do seem to be apparent across studies and therefore it is fair to make tentative assumptions as to the psychological needs of individuals with dementia based on these studies.

2.3.4 Psychotherapeutic Models

This section is mainly focused on psychotherapeutic models applied on an individual basis. It is, however, acknowledged that group psychotherapy is widely utilised in the dementia field (see Cheston, Jones & Gilliard, 2003; Scott & Clare, 2003). Although touched upon in this section, critical evaluation of group work is beyond the scope of this review.

2.3.4.1 Humanistic approach

Developed from a number of approaches, such as person-centred, Gestalt and existential therapy, the humanistic paradigm focuses on an individual's need for self-fulfilment or self-actualisation. From this perspective, human experience is understood in relation to several concepts, including process, reflexivity, sense of self, embodiment and experiencing (McLeod, 2003).

In the past, humanistic or person-centred approaches have been questioned in relation to dementia. Given that as an approach they are client-led based on the perceptions and experiences of the individual, the work was perceived to be challenging when working with individuals with dementia, who have difficulties in these areas (Norman & Redfern, 1996). Prior to Kitwood's (1990) psychosocial model of dementia, in which person-centred ideas were at the forefront, humanistic concepts had already begun to be employed in dementia care (Bender & Cheston, 1997). A number of therapies were developed specifically for individuals with cognitive impairment, such as those with dementia which have been applied on an individual and group basis. One such approach was reality orientation, which aimed to orient the individual with dementia to place, time and person by making information available that the individual has lost through the disease (Brooker, 2001). Reality orientation can be simply achieved in a number of ways, for example, through the use of calendars or clocks and by bringing individuals up to date with current affairs through the use of individual or group discussion (Thompson, 1997). Brooker (2001) has highlighted that reality orientation, although appearing simplistic in nature, has been valuable as a therapeutic tool to improve confidence and enhance well-being. The research literature in regard to the effectiveness of reality orientation is limited, however, and dates back to pre-1990. Around this time, the approach met with heavy criticism for being inflexible and insensitive (NICE, 2006). It was also criticised for its failure in supporting individuals in the later stages of dementia (Stokes & Goudie, 2002) and as a result little research was completed following this. More recently, however, Spector, Davies, Woods and Orrell (2000) completed a systematic review of the evidence for the effectiveness of reality orientation in dementia. In the review, 43 studies were identified of which six randomised controlled trials were included in the analysis. The review established that reality orientation appeared to be beneficial for both cognition and behaviour although it was acknowledged that these findings may not extend beyond treatment. Whilst this review was clearly well controlled in terms of its strict inclusion criteria, it would have been interesting to have examined the additional studies that were excluded. These may have provided additional information as to the effectiveness of the reality orientation approach, for example, if a qualitative paradigm had been employed it may have provided valuable insight as to the experience of individuals receiving reality orientation from this different perspective.

In response to the criticism of reality orientation, and heavily influenced by Rogerian and psychoanalytic traditions, validation therapy was developed by Naomi Feil (Morton, 1999). Validation therapy focuses on the emotional experience of the individual with dementia (Brooker, 2001). There are a number of key techniques that are applied in this approach. The function of challenging behaviours, for example, is examined in order to identify unmet needs. Language is used as a tool to centre the individual in order to build trust and acceptance. The therapist in validation therapy also attempts to match the individual's motions and emotions and genuine eye contact is maintained. The aims of these techniques are to promote dignity and trust, to provide empathy, respect and acceptance towards the individual and to prevent further deterioration (Neal & Barton Wright, 2003). In a systematic review consisting of three studies, Neal and Barton Wright (2003) examined the efficacy of validation therapy for both individuals and groups in dementia. Given the small number of studies analysed, it was established that there was insufficient evidence to determine any particular outcome concerning the efficacy of validation therapy. Despite the limited outcome, the review was helpful in highlighting the variation in interventions which were considered to be validation therapy. It also highlighted the limitations of outcome measures used and the heterogeneity of samples thus making evaluation difficult. Consequently, further research of validation therapy is required in order to address these methodological limitations and to determine whether it is a valuable method. Validation therapy has also been criticised for mixing different approaches and for a lack of transparency over the target population considered for the approach (Stokes & Goudie, 2002).

Challenging, in particular, the psychodynamic components of validation and use of interpretations, Goudie and Stokes (1990) developed resolution therapy, which draws on humanistic concepts and encourages empathy with the hidden meanings and understandings believed to be behind the confusion expressed by individuals with dementia (Cheston, 1998). Using skills such as reflection, exploration, warmth and acceptance the therapist can attempt to understand and respond to the feelings of the individual diagnosed with dementia (Goudie, 2003). Morton (1999), however, emphasised that Goudie and Stokes left many unanswered questions in their approach, particularly in examining the therapeutic relationship with an individual with dementia, a key component of the Rogerian perspective. Currently, there appears to be some anecdotal evidence from Goudie and Stokes (1990) suggesting that it is a valuable approach in working therapeutically with individuals with dementia. However, to date, there does not appear to be any compelling research evidence to support the effectiveness of this approach thus making its value questionable.

Following the trend for developing a person-centred approach in the dementia field, pre-therapy came to light, originally developed by Garry Prouty (1976) in the context of mental illness. Focused on engagement with individuals, the aim of pre-therapy is to bring individuals, such as those with dementia, back into psychological contact where this has diminished. This is achieved through the use of contact reflections in which observations of the surroundings, the individuals' affect and verbal/non-verbal expression are reflected back to them. This enables the individual to regain a sense of reality, affect and communication (Van Werde & Morton, 1999). Whilst there is some anecdotal evidence as to the effectiveness of pre-therapy with people with dementia, further and more rigorous research is required to develop the evidence base for this approach (Dodds, Morton & Prouty, 2004).

Whilst these humanistic models have been widely used in dementia care and anecdotal evidence is apparent for some approaches, it is clear that further research is warranted to fully establish their effectiveness. A number of methodological limitations have been highlighted in the systematic reviews of the current research literature surrounding these approaches and these would also need to be addressed. Additionally, some of the approaches have been criticised for moving too far away from their humanistic roots (Norman & Redfern, 1996).

2.3.4.2 Cognitive Behavioural Therapy

Cognitive Behavioural Therapy (CBT) is an integration of cognitive (Beck, 1970) and behavioural (Bandura, 1977) approaches aiming to alleviate emotional disturbance by assisting individuals in recognising and challenging their maladaptive beliefs and behaviours. CBT assumes that the individual's experiences relate to four interacting elements – cognition, emotion, physiology and behaviour. The model intimates that an individual's core beliefs and assumptions about themselves and the environment are significant in constructing and maintaining these four elements. Intervention primarily occurs at the cognitive and behavioural levels (Scott & Dryden, 2003).

Within the dementia literature there is strong evidence for the value of psychological interventions for the reduction of stress in caregivers (Burns et al., 2005). Marriott, Donaldson, Tarrier and Burns (2000), for example, evaluated whether a CBT based family intervention reduced the subjective burden of care in 42 caregivers of individuals with Alzheimer's disease, in a single-blind randomised controlled trial. The intervention consisted of three aspects which were carer education, stress management and coping skills training over 14 sessions and it was compared to a no intervention control group. Through interviews and self-report measures it was established that there was a significant reduction in distress and depression in the CBT group compared to the control which was sustained at a three month follow-up. A reduction in behavioural disturbance was also observed in the individuals with dementia although this was not maintained at follow-up. Whilst this study established positive results, it could be criticised for having a relatively small sample for a randomised controlled trial and there may have been an element of bias in that the same individual performed the assessments and carried out the intervention. It would also have been interesting to examine whether there were particular components of the intervention that were most effective and to have compared the intervention to other approaches.

The value of CBT in a group setting has also been highlighted in the literature (Scott & Clare, 2003). Kipling, Bailey and Charlesworth (1999), for example, evaluated the use of CBT in a memory group focused on challenging maladaptive memory-related beliefs. Three men diagnosed with probable dementia took part in a seven session group which included discussion of memory difficulties and had a psycho-educational component. It was concluded that sharing experiences with other individuals with dementia was a valuable way of challenging unhelpful beliefs. The study, however, appeared to be limited by its small sample size and would have benefited from being compared with a control group and perhaps including a female sample.

On an individual basis, CBT has mainly been adopted by clinicians for those with dementia to reduce both anxiety and depression (Bender & Cheston, 1997). The approach has also been employed as a means to assist individuals with dementia in adjusting to their changing world (Maciejewski, 2001). According to Kasl-Godley and Gatz (2000), in a brief overview of interventions used with individuals with dementia, a number of factors are significant to the CBT work. Of particular importance is enabling the individual to develop techniques to identify and increase pleasant events, assisting them to develop awareness of the link between their thoughts and feelings and supporting them to identify and challenge their distorted negative thinking.

Teri and Gallagher-Thompson (1991) proposed both a cognitive and behavioural intervention for treating depression in individuals with mild through to severe Alzheimer's disease. The cognitive component focused on challenging the individual's negative cognitions and supporting the individual in generating alternative more adaptive ways of perceiving events. Whilst in contrast, the behavioural approach focused on increasing positive activities. The approaches were evaluated through clinical practice using self-report outcome measures. A decline in depression scores was observed along with a reduction in self-reported caregiver strain. Whilst this paper is useful as a form of practice-based evidence, it is apparent as the authors themselves acknowledge, that the approaches require more rigorous evaluation before any firm conclusions can be drawn as to their effectiveness. More recently, however, Scholey and Woods (2003) addressed this gap in a study of seven individuals with concurrent dementia and depression. Participants took part in an eight session cognitive therapy group modified slightly to accommodate the dementia diagnosis. The outcome of the cognitive intervention was assessed using the Geriatric Depression Scale which is a 30-item self-report measure validated to evaluate changes in mood (Yesavage et al., 1983). The study established that cognitive therapy produced a moderate reduction in depressive symptoms experienced by individuals with mild to moderate dementia. Additionally, the study highlighted that impaired cognitive abilities did not appear to impede the therapeutic process. Whilst this study appears to advance the research literature on CBT and dementia, some methodological limitations were apparent. Most noticeably, the study was not compared to a control group and at least one of the participants was prescribed a mood enhancing drug during the course of the intervention which could have impacted on the results. What was interesting, nonetheless, was that the study appeared to take on a qualitative feature emphasising common themes that arose during therapy. This seemed to provide the study with an additional and valued depth of data that was not reached through the quantitative component.

Balasubramanyam, Stanley and Kunik (2007), highlighted a case study in which a modified CBT approach was utilised successfully in the treatment of anxiety in a 76 year old man diagnosed with dementia. The researchers emphasised a number of optimal learning strategies to be employed with individuals with dementia and advocated caregiver involvement in the work. The case study consisted of ten weekly sessions of individual CBT in which the man was encouraged to monitor his anxiety symptoms and was taught breathing techniques to manage the physiological aspects of his anxiety. Improvement was observed on a number of different self-report outcome measures. Despite this positive result, the study can be criticised given its limited sample and the lack of follow up to assess whether the results were maintained. Additionally, the individual was telephoned between sessions to ascertain his progress with the techniques taught in session which, in a demanding clinical service, may not be feasible. Earlier studies, such as Koder (1998), also appeared to have similar methodological limitations despite displaying some initially positive results in the cognitive-behavioural treatment of anxiety in dementia. Consequently further, more rigorous, studies would be beneficial.

Although to date there is a lack of rigorous clinical trials of CBT in dementia, the existing evidence does indicate some positive results for the effectiveness of the approach with this population. Balasubramanyam, Stanley and Kunik (2007) identified three aspects they considered to be supportive of the effectiveness of CBT in dementia. Firstly, they established a number of clinical cases reporting the success of the approach. Secondly, they emphasised that CBT is employed effectively with other populations with cognitive impairments and thirdly, they highlighted compelling evidence for the use of behavioural techniques in dementia work. Despite these findings, it is apparent that further research with larger sample sizes would be beneficial in order to attempt to replicate these findings and to examine any longer term benefits of CBT for the dementia population.

2.3.4.3 Psychoanalytic / dynamic therapy

Psychoanalysis or psychodynamic therapy is concerned with how awareness of the past, and perceptions developed from past experience, inform the present way of being, thinking and behaving with a particular emphasis on the relationship between client and therapist (Jacobs, 2006).

Initially, Freud considered psychotherapy with older people, including individuals with dementia, as unsuitable due to his view that such individuals did not possess the appropriate cognitive resources and so the area received little empirical attention (Maciejewski, 2001). More recently, however, a psychoanalytic or psychodynamic approach to dementia has been described more widely in the literature. From this perspective, it is proposed that the process of dementia may impact upon the sufferer's ability to utilise defence mechanisms to protect their increasingly fragile self (Bender & Cheston, 1997). Expanding on this concept further, Kasl-Godley and Gatz (2000) proposed that in the earlier stages of dementia the ego attempts to defend from the losses associated with dementia using defence mechanisms such as denial, projection or splitting. As the dementia progresses, it is proposed that individuals with dementia struggle to preserve their sense of self and therefore become dependent on their significant others. During the later stages of the disease, it is suggested that the individual's defence mechanisms fail or become more primitive leading to increased feelings of distress, agitation, aggression and isolation. Thus the main focus of treatment using this approach is on maintaining a sense of self through a secure and accepting therapeutic relationship in which the individual feels understood and supported (Hausman, 1992). Solomon and Szwabo (1992) also emphasised that the main goals of this approach are to reorganise the self to integrate the disease process, enhance coping skills and to reduce emotional stress. An additional line of research has considered the concept of attachment to develop understanding of the experience of individuals with dementia (Cheston & Bender, 1999). In an explorative study of 40 participants with Alzheimer's disease, for example, Miesen (1993) applied the theory of attachment to explore parent fixation, in which individuals with dementia perceive their deceased parents to be alive. Creating and observing an experimental family visit, a number of important relationships were established between attachment behaviours, level of cognitive impairment and parent fixation. Firstly, it was identified that the process of dementia can be understood as a strange situation in which the more unsafe the individual feels the more attachment behaviour is displayed. As the individual progresses into the later stages of the disease so the more prominent the strange situation becomes and subsequent display of attachment behaviour. Parent fixation is consequently understood as a form of attachment and is particularly apparent where no other available attachment figure is present. This study appears to provide a valuable understanding of the dementia experience from the perspective of attachment theory. Miesen (1993), however, acknowledged that despite the interesting results of this study other theoretical frameworks can also be employed to understand the dementia experience.

As outlined above, there appears to be an abundance of literature in the field of dementia describing the psychoanalytical or dynamic approach but given that it is not empirical literature it has not been critiqued to a great extent in this review. However, it is perceived to be a valuable way of conceptualising the difficulties faced in dementia. There is, in fact, limited evidence to support the efficacy of the psychoanalytical or dynamic approach with individuals diagnosed with dementia (Kasl-Godley & Gatz, 2000). Where empirical support is available, the research has mainly focused on small case studies drawing on psychoanalytic theory to make conclusions about the value of the work (for example, Sadavoy, 1991). Sinason (1992) described a piece of psychoanalytic work with an academic male who had developed Alzheimer's disease at the age of 56 years old. The case study described the therapeutic process from the first session to the end of therapy highlighting her interpretations of the work during the course of the therapy. Whilst this case study is an interesting and moving account of psychoanalytic therapy with an individual with dementia indicating the value of this work, it is difficult to draw wider conclusions as to the effectiveness of the approach. Consequently, although these studies, such as the one outlined here, provide an indication of the effectiveness of the approach in working with individuals with dementia, the results appear somewhat speculative and further empirical research would be valuable.

2.3.4.4 Systemic approach

The systems paradigm emphasises the importance of considering psychological difficulties within a social or political context. Thus patterns of behaviour in an individual are understood in relation to the behaviours being preserved through feedback from the wider system such as the family or system of care (Bor & Legg, 2003). Historically, older people have been involved in systemic work in their roles as caregivers and they have rarely been recognised as the individual with the problem within the family system (Maciejewski, 2001). However, more recently a systemic approach has been employed with individuals with dementia both within the family system and within institutional care settings. From this perspective, it is recognised that as a result of one individual within the family system being diagnosed with dementia, the roles, relationships and goals of other family members within the system will also be impacted upon (Kaplan, 1996). Furthermore, the experience of an individual with dementia can be viewed as being constructed within a social context (Robinson, Clare & Evans, 2005), thus a systemic perspective may be helpful in reflecting on family processes in dementia (Hanson, 1997).

Although the research in the area of systemic therapy and dementia is limited there is a recently growing body of research which has investigated relationship dyads in dementia drawing on systemic theory (Davies & Gregory, 2007). Braun et al. (2009) completed a literature review examining the extent to which a dyadic perspective is apparent in the literature. The review identified a number of studies focusing on either the caregiver or individual with dementia, whilst fewer studies were evident that focused on the dyadic relationship in dementia, although the importance of this research was made apparent in the existing literature. The five studies that did focus on the dyadic relationship appeared to be quantitative studies mainly exploring the impact for the caregiver according to self-report measures. Consequently, they provided very little insight as to how dementia was experienced by couples and did not seem to consider any theoretical elements in the research, both of which would have been valuable in developing systemic interventions in the dementia field.

In contrast, a qualitative study completed by Robinson, Clare and Evans (2005) explored the experiences of nine couples from a family systems perspective in which one of the dyad had received a dementia diagnosis. The researchers were particularly interested in understanding couples' psychological responses to, and constructions, of a diagnosis of dementia in the context of loss and adjustment. Joint interviews were completed with each of the nine couples and the transcribed data was analysed using Interpretative Phenomenological Analysis (IPA: Smith, Jarman & Osborn, 1999). Two higher order themes were identified from the analysed data. The first theme illustrated a process of gradually noticing changes in the individual with dementia and making sense of this process as a couple. Secondly, a process of adjustment was apparent in which couples accepted their losses and acknowledged their resilience and identified coping mechanisms. The themes were developed into a framework which provided helpful insight into how these couples jointly made sense of, and adjusted to, the dementia diagnosis. Further research would be beneficial, nonetheless, in order for this framework to be applied more generally to the dementia population. For example, as Robinson et al. (2005) emphasised, it may be useful to examine other family pairs, such as parent-child, or to consider the model in the context of the couples who declined to take part in the study and who may have a different adjustment experience. One important consideration for this study was that the interviews were completed with the couple together. This may have influenced how much each individual was willing to say in the interviews or what position they might have taken in front of their partner or the interviewer. Although this could be considered a limitation of the study, it might equally provide further insight into the couples' experiences.

A more recent qualitative study completed by O'Shaughnessy, Lee and Lintern (2010), explored changes in the couple relationship according to the spouse caregivers' experiences. In the study, seven spouse caregivers of partners diagnosed with dementia were interviewed about their experiences. The transcribed data was analysed using IPA (Smith et al., 1999) and four themes were identified from the participants' accounts. The spouse caregivers seemed to reflect on their past and current relationship holding on to their status as a couple whilst feeling increasingly separated from them. Tensions appeared to arise between meeting their own needs and those of their spouse. Fluctuation was observed between participants' acceptance of the future and the uncertainty of what the future might hold. Finally a lack of control was expressed by the spouse caregivers regarding the changes to the relationship and practical strategies were developed in order to cope. Whilst only focusing on the experience of the spouse, the study provided a significant insight into the changes occurring for these couples. In particular, themes were identified that were also evident in the study by Robinson et al. (2005). The notion of movement between different positions was apparent in both studies as the couples adjust to the progressive nature of the dementia. Furthermore, the importance of identity loss and changing roles for the couples was evident in both studies. It would have been beneficial to have explored the experiences of the partners with dementia in addition to the spouse carer as their contribution would have been equally as valid. The participants who were chosen to take part all cared for their partners at home. Although in terms of homogeneity this was useful, future research could, for example, look at couples where the partner is in residential care.

These studies are valuable in furthering the understanding of one aspect of a system, the couple relationship. It is apparent, however, that further research is required to examine other aspects of the system surrounding an individual with dementia and to investigate the application of systemic therapy with the dementia population in more depth.

2.3.5 Factors Affecting Use of Psychotherapy with Individuals with Dementia

2.3.5.1 Adaptations to therapy

Within the psychotherapy literature, some of which has been critiqued above, a number of adaptations to therapy have been highlighted when working with individuals with dementia. Within CBT several adaptations have been noted including; structuring sessions extensively, reducing the amount of information to be remembered, using concrete examples and external aids and frequently checking the individual's understanding of the therapeutic process (Kasl-Godley & Gatz, 2000). Scholey and Woods (2003), in their study critiqued above, whilst exploring cognitive therapy interventions with individuals with concurrent dementia and depression also emphasised the importance of adapting the therapy for individuals with dementia. Therapists in the study played a more active role in setting the agenda at the beginning of sessions and regularly attempted to summarise significant aspects of the therapy. Additionally, where discussion of secondary issues occurred, moving away from the central focus in the therapy, these could be drawn back into the central discussion and were thought to facilitate rapport. Finally, considering the diagnosis and associated cognitive changes appeared to be a central part of the work. Similarly to the CBT literature, several adaptations have also been suggested when working from a psychodynamic approach with individuals with dementia. Solomon and Szwabo (1992), for example, referred to the importance of making concrete interpretations with clients as opposed to the use of abstract or existential ideas and reducing the use of transference or confrontation in therapy.

2.3.5.2 Challenges to therapy

As might be expected, there are some significant challenges when working psychotherapeutically with individuals with dementia. Much of psychotherapy is client led and this can create tension for a therapist where the client with dementia has difficulties recollecting or communicating distressing elements of their experience. Being more proactive in order to counteract this difficulty may risk leading the client and, consequently, this creates a dilemma for the therapist (Bartlett & Cheston, 2003). Individuals with dementia are often placed in environments in which they are cared for in some form, whether within the family home or care context. Thus, for therapists, there is often a need to liaise with other individuals about the client. This could create boundary dilemmas and ethical issues around confidentiality (Bartlett & Cheston, 2003). Furthermore, within the system a therapist might find themselves acting to protect the client from the negative assumptions of individuals around them (Maciejewski, 2001). The implications of which might be the creation of tension amongst the system and difficulties challenging the assumptions of others, which are often deeply ingrained. Given the changing needs of an individual with dementia delineating an end point for the therapy can also be a challenge. A therapist might, for example, end the therapy too soon or continue for longer then is helpful thus potentially damaging the therapeutic work that has been done. Additionally, given the likely deterioration of an individual with dementia, capacity to consent to therapy can also be an ethical consideration for therapists to overcome (Bartlett & Cheston, 2003). Bender and Cheston (1997) also emphasised that working with individuals with dementia is particularly challenging in drawing attention to the therapist's own emotional world and especially in facing up to inevitable losses. This could lead to considerable distress for the therapist which might in turn have an impact on the therapy. Additionally, there is the challenge of being compelled towards a tendency in the relationship to infantilise clients. Furthermore, failing to recognise the client's potential and/or their subjective experience could be detrimental to the therapeutic relationship and ultimately to the therapy itself.

2.3.6 Experiences of Psychotherapy

Whilst it is apparent from this review that there is a wide expanse of literature exploring psychotherapeutic intervention as a means of alleviating psychological distress associated with a diagnosis of dementia, less research has focused on the actual experiences of psychotherapy. For example, what it is like to have psychotherapy as an individual with dementia, or to be a psychological therapist working psychotherapeutically with this population?

2.3.6.1 Insight from other professionals

There appears to be limited empirical research exploring professionals' perceptions of psychotherapy with individuals diagnosed with dementia. For example, in the process of developing a dementia counselling service in Tayside UK, Weaks, McLeod and Wilkinson (2006) completed a qualitative study comprising semi-structured interviews with 12 General Practitioners, seven Psychiatrists and two Community Psychiatric Nurses. The professionals who were interviewed advocated the development of services offering psychotherapy to individuals diagnosed with dementia. Several therapeutic tasks were proposed as important factors to guide therapists. These included empowering individuals to continue life as normal, understanding the changing roles in their relationships, understanding the emotional process of the dementia diagnosis and addressing philosophical questions relating to the diagnosis of dementia. Also of importance was embracing both internal and external stigma and creating a different identity to incorporate the diagnosis. Whilst this was a valuable study, it is assumed that none of these professionals actually had experience of working psychotherapeutically with individuals with dementia and therefore the results seem to be speculative.

Lipinska (2009) has written a book exploring the value of counselling for individuals with dementia based on her own experience of counselling this client group. Drawing on discussions with professionals and other individuals working in the field of dementia, Lipinska highlighted that professionals across different care services had expressed surprise regarding the outcomes of therapy with the dementia population.

Care staff also expressed a sense of relief that somebody was available to offer individuals with dementia the time they needed. These findings, however, are anecdotal and seem to contribute little to developing empirical research in this area.

2.3.6.2 Individuals with dementia

Given that only in recent years has there been an expansion in research examining psychotherapy in dementia and the subjective experiences of individuals with dementia have only recently been considered, it is not surprising that there is little research exploring the experiences of psychotherapy in individuals with dementia. In a paper reflecting on psychotherapeutic approaches in dementia, Bryden (2002), who has a diagnosis of early onset dementia, put forward her own personal insight into psychotherapy for individuals diagnosed with dementia. It was observed that personality, biography and spirituality were significant factors in psychological intervention. Psychotherapy was perceived by Bryden (2002) to be beneficial in assisting individuals to reframe their perspective surrounding the diagnosis. The uniqueness of individuals, in terms of the variety of experiences they bring to the dementia picture, was also emphasised as being a significant focus for effective treatment. This paper, predominantly a review of the psychotherapy literature, seems to also incorporate aspects of Bryden's own perceptions of psychotherapy. It is consequently unclear at times what she has inferred her self and what might be established research. Therefore it is difficult to draw any firm conclusions from this research in regards to the experience of psychotherapy for individuals with dementia.

Lipinska (2009) brought to light a number of examples of the experiences of counselling from the client's perspective which had arisen in her work. For one client, the counselling enabled a sense of control to be gained where this was lost through memory problems. For other clients, Lipinska (2009) suggested that the counselling provided a space to unburden their experiences and to tell their story freely and to have their experience validated. For yet other clients, counselling facilitated a process of resolution and forgiveness. Whilst these examples are interesting, the findings can again be criticised for being mainly anecdotal and therefore lacking in empirical research. Lipinska (2009) also seems to generalise from these examples drawing conclusions about the wider dementia population. Despite this, these ideas are informative for therapists, such as counselling psychologists, in terms of developing an understanding of how counselling might be helpful for individuals with dementia.

2.3.6.3 Psychological therapists' experiences

Only a few studies have been identified that examine psychological therapists' experiences of working with individuals with dementia. Mosher-Ashley and Witkowski (1999) in a quantitative study consulted therapists based in Massachusetts, United States of America (USA) on their experiences of providing psychotherapy to individuals with dementia. Using postal questionnaires, the study examined 27 therapists' perceptions of services provided to individuals with cognitive impairments, including dementia. Questionnaires containing both closed and open questions were sent out to therapists within mental health centres to examine the benefits observed in working with individuals with dementia and common problems encountered during the therapeutic process. The therapists provided a range of counselling services to individuals with dementia and their families. They considered the main reasons for referral to be due to symptoms of depression, anxiety over cognitive losses, feelings of anger or frustration, and for management of disruptive behaviour. The therapists perceived the benefits of counselling for individuals with dementia to be a decline in anxiety and depression, and an increased understanding of, and adjustment to, the disease. They also highlighted a benefit for caregivers and family in terms of a reduction in caregiver stress. Therapists also experienced a number of difficulties when counselling individuals with dementia. They found that due to limitations in cognitive decline, such as difficulty remembering or processing information, poor expressive skills and difficulty understanding the therapist's role, continuing therapy was not always effective. Client denial of dementia, resistance to treatment and difficulty forming relationships were also experienced as challenging factors for therapists to manage. Whilst this study provided a valuable insight into therapists' experiences of working with individuals with dementia, a number of limitations have been observed. Firstly, the researchers did not define clearly the term 'therapist' and consequently it is difficult to ascertain whether the findings can be applied more generally, such as, to counselling psychology practice. The study also appeared to be restricted somewhat by the quantitative methodology employed. Although open questions were utilised in the questionnaires, by using this approach it was not possible to follow up particularly interesting lines of inquiry with participants and as a consequence the results do not seem to capture the essence of the therapists' experiences on a deeper level which would have provided an additional richness to the data. Furthermore, the study was based on work in the USA and therefore the experiences of therapists may be considerably different to those working in the UK. For example, services are likely to be funded differently which may impact on how therapists experience their work and the types of clients that are referred to services.

Lipinska (2009), discussed in previous sections above, reflected on her own experience of counselling individuals with dementia coming from a person-centred perspective. Acknowledging that she mainly works with individuals with dementia as she would with any other adult client, she highlighted a number of differences in working with this group. In particular, she considered the need for clarity, checking understanding and regularly reviewing sessions to be more significant when working with individuals with dementia. Furthermore, she made reference to her role of holding on to her clients' memories for them and also highlighted the importance of ensuring that the individual remained at the centre of the counselling experience involved in the process of creating the therapeutic relationship and agenda. Although valuable, these ideas are only based on a single therapist's anecdotal experiences of working with individuals with dementia, making wider application difficult.

It can be seen, therefore, that these few studies make some attempt to examine therapists' experiences of working psychotherapeutically with individuals with dementia, as well as other professionals' perceptions of psychotherapy with this group, and the perceptions of individuals with dementia themselves. While the studies do progress the literature in this area, it is nonetheless evident that the research is limited in a number of ways. The quantitative studies, for example, can be criticised for lacking depth in their findings. A richness of data would be particularly valuable when exploring the experiences of a phenomenon, such as therapists' psychotherapeutic work with individuals with dementia. Furthermore, some of the other findings discussed appeared to be more anecdotal than empirical and consequently are difficult to apply more widely. Additionally, the existing empirical research seemed to focus more on the benefits and challenges to therapy with the dementia population not taking into consideration the whole experience as perceived by the individual therapist and could therefore be considered as inconsistent with the philosophy of counselling psychology (BPS, 2005). The research also appears to pay less attention to specific components of the therapeutic process, such as the therapeutic relationship. The therapeutic relationship is a particularly significant aspect of counselling psychology practice (Strawbridge & Woolfe, 2003) and as such focusing more specifically on this area in the dementia research would be informative for the discipline. It could, therefore, be suggested that further research exploring what it is actually like as a psychological therapist working psychotherapeutically with individuals with dementia would be beneficial to address the deficits outlined. Progression in this area would be significant for developing further understanding of aspects of the psychotherapeutic work, including therapeutic processes, to inform clinical practice, particularly for counselling psychologists. Given the more recent focus on dementia born out of the National Dementia Strategy (Department of Health, 2009), it is postulated that treatment such as psychological interventions will be increasingly brought to light as beneficial for the dementia population. Therefore, studies such as this will be valuable in informing that future work. Furthermore, given that there still remains some question surrounding the potential for psychotherapeutic work with individuals with dementia, additional research would be valuable in raising awareness of the possibilities for this work.

2.4 Therapeutic Processes including the Therapeutic Relationship

This section examines the literature surrounding therapeutic processes, including the therapeutic relationship, and provides the reader with an explanation of these concepts in the context of dementia.

2.4.1 Definitions and Perspectives

Within psychotherapy, the therapeutic process can be defined as a set of procedures that occur during therapy. Within the psychotherapeutic literature, therapeutic processes have been examined in depth. Of particular interest, is the link between process and outcome and there exists an ongoing debate as to which variables are important to bring about therapeutic change (Goldfried & Davila, 2005). Norcross (2002), for example, explored the literature regarding predictors of outcome in psychotherapy. It was established that outcome is associated with factors such as expectancy effects, therapeutic techniques, and common factors shared by all psychotherapies, including the therapeutic relationship.

The relationship between the client and therapist, a central element of the ongoing debate, has been acknowledged to play a fundamental role in the therapeutic process and outcome of therapy (Bachelor & Horvath, 1999). The therapeutic relationship (also defined as: *working relationship*, *therapeutic alliance* or *therapeutic bond*) was first acknowledged by Freud (1940) as being important to the therapeutic process. Of particular significance were the concepts of transference, a client's unconscious identification with the therapist based on past relational experiences, and counter-transference, a therapist's unconscious feelings towards the client based on their own relational experiences. Rogers (1951) considered the therapeutic relationship to be a meaningful encounter and documented the essential qualities of empathy, genuineness and unconditional positive regard as being necessary and sufficient for any therapeutic relationship to bring about client change. Many of these ideas were challenged by early classical behaviourists consequently leading to an expanse of research in the area (Bachelor & Horvath, 1999). Of significance, Greenson (1965) developed the concept of the alliance, distinguishing between the task-focused working alliance and the therapeutic alliance or personal bond. Expanding on these ideas and broadening them to incorporate all forms of psychotherapy, Bordin (1979) cited three fundamental features of the therapeutic alliance, emphasising the role of the client to the relationship. Firstly, therapeutic tasks involve the processes within the therapy session comprising the actual work of the therapy. Secondly, therapeutic goals concern the objectives of therapy that both client and therapist work towards. Finally, the development of bonds, in which the interpersonal relationship based on trust and acceptance between client and therapist is realised.

There have been consistent reports throughout the research literature demonstrating a positive relationship between the therapeutic alliance and outcome in therapy although discrepancies exist within some research (Lambert & Barley, 2001). However the ongoing debate, particularly between the role of therapeutic techniques and the therapeutic relationship in outcome research, remains (Goldfried & Davila, 2005). Further research is still outstanding delineating to how different aspects of the therapeutic alliance are connected to the change process and how specific variables, such as clinical presentation, may influence this process (Goldfried & Davila, 2005). A further area of interest in the therapeutic relationship literature, also worth considering briefly in this section, is the divergence between therapist and client reporting of the therapeutic relationship. Studies exploring this aspect have suggested that clients and therapists differ in their perceptions of the quality of the therapeutic relationship (Bachelor & Horvath, 1999). For example, Tryon, Blackwell and Hammel (2007) in a meta-analysis examining client-therapist perspectives of the therapeutic relationship, observed that in the majority of studies clients and therapists appeared to view the relationship differently with clients giving higher alliance ratings in the main. Overall a moderate correlation was established in the meta-analysis between client and therapist alliance ratings although it was identified that convergences and divergences were apparent. Additionally, as highlighted by Timulak (2010) in a review of significant events research, clients' perceptions in therapy often differ from that of therapists with the relational and emotional aspects of significant events considered as more important to clients than therapists. Given the wide expanse of literature in this area further critique of these studies is beyond the scope of this literature review. As there is both divergence and convergence in relation to client and therapist reporting in therapy, it therefore seems to be important to examine both views in research. Within the philosophy of counselling psychology, the therapeutic relationship is regarded as the central tenet of the therapy in which a process of self-actualisation is realised regardless of the presenting problems (Strawbridge & Woolfe, 2003). Significant to this relationship is the focus of *being with* clients rather than *doing to* them. Consequently the therapist is perceived to be an active part of the therapeutic process in which a mutual understanding is reached between therapist and client (Strawbridge & Woolfe, 2003). Given this dynamic position, it is therefore perceived valuable to examine further the experiences of therapists in their work, such as for example, when working with individuals with dementia.

2.4.2 Considerations of Therapeutic Processes in Dementia

Whilst much consideration has been given to the therapeutic process and particularly the therapeutic relationship in mainstream psychotherapy and counselling psychology research, there has been little consideration of the therapeutic process when working psychotherapeutically with individuals with dementia. A small body of research, however, has focused on the therapeutic relationship when working with individuals with dementia. Bartlett and Cheston (2003) highlight the importance of therapeutic engagement in all therapeutic relationships, but particularly when working with individuals with dementia in which it needs to be made more explicit. It was suggested that this is particularly important given the potential for client difficulties in understanding a therapist's role and given that in the process of gaining a diagnosis individuals may have come across a confusing number and range of professionals. Awareness of the therapeutic relationship, and especially the psychodynamic concepts of transference and counter-transference, have also been emphasised as important when working psychotherapeutically with older adults in general and more specifically those diagnosed with dementia. For example, Semel (2006), in a theoretical piece of writing drawing on research and clinical practice, reflected on counter-transference concepts when working with older adults, including those with dementia. The therapist's reaction to their own aging and death were considered to be particularly significant in counter-transference reactions with this client group. The therapist's holding of unresolved feelings towards their own parents was also considered to be an important area for therapists to be aware of. Although this is interesting, it would be of more value to consider these concepts further in empirical research and to focus on counter-transference concepts with dementia clients specifically.

A case study approach has been utilised as a way of exploring the therapeutic relationship with individuals with dementia. Greenwood and Loewenthal (1998), using a single case study design, explored whether it was possible to have a therapeutic relationship with an individual diagnosed with dementia. Of particular interest, the study emphasised the notion of bringing preconceived ideas into the relationship. In this particular case, this was explored through an example in which the therapist had missed the first appointment with the individual with dementia and did not perceive it to be an issue given the client's presentation of dementia. Additionally, the therapist described becoming focused on attempting to understand the meaning of the client's words, perhaps concerned with the shortcomings of language and difficulties in expressing meaning, to the apparent detriment of the therapeutic relationship. Reflecting on these processes, it was suggested that the client's diagnosis of dementia was very much influencing the therapist's behaviour. This provides a useful understanding of the therapeutic relationship between a therapist and client with dementia and demonstrates the need for therapists to hold awareness of their own fore-understandings in their relationships with clients with dementia. Given that this was an individual case study, it would be helpful to examine the notion of preconceived ideas in further empirical research.

Overall, this literature provides some useful reflections in relation to therapeutic processes, and particularly the therapeutic relationship, which can be considered in light of clinical practice with individuals with dementia. Despite this, there is little other research in this area, and the studies mainly focus on single cases making it difficult to draw conclusions more widely. It could be suggested, therefore, that further research exploring the process of therapy, and particularly the therapeutic relationship, would be valuable to address this gap in our understanding. Given the importance placed upon the therapeutic relationship in counselling psychology, this is an area that would be valuable to explore further to inform counselling psychology practice in the dementia field.

2.5 Position of Psychological Therapists

Clinical and counselling psychologists as a profession can be considered to hold both similarities and differences in terms of their training and clinical practice. In particular, both professions can be seen to adhere to a scientist-practitioner model and are compatible in terms of drawing on similar theoretical frameworks and interventions (Bury & Strauss, 2006). Thus, in terms of how both professions 'do' therapy, they could be considered to be relatively similar. However, one key difference evident in the recent Standards of Proficiency for Practitioner Psychologists set by the Health Professions Council (HPC: 2009), is that counselling psychologists appear to place greater emphasis on reflexivity in their practice, for example, in critically reflecting on the use of self in the therapeutic process. Additionally, as highlighted at the beginning of this review, counselling psychologists place a particular emphasis on the quality of the therapeutic relationship and respect for the subjective experience of the client, whereas, perhaps more traditionally for clinical psychologists, these aspects appear to be less important (Bury & Strauss, 2006). However, this is still an area of considerable debate that is beyond the scope of this literature review, and could be argued to be cause for some over generalisation between the two applied fields. Taking these aspects into account, and the practicalities of this research, the researcher has taken the position that the two professions are sufficiently similar in that both clinical and counselling psychologists are in a prime position to offer an important contribution to the understanding of psychotherapeutic work with individuals diagnosed with dementia. Furthermore, as suggested by Bury and Strauss (2006), rather than reflecting on the two professions as separate entities it is possible to view them as falling on a continuum. Thus, in this context, both professions are able to make a valuable contribution to counselling psychology research. Importantly, both disciplines have propelled the move away from the medical model and ideas of pathology, towards supporting the psychological wellbeing of an individual (Strawbridge & Woolfe, 2003). Within the area of dementia, there has been a parallel move away from the medical model of dementia as a disease process and towards a psychosocial model where the experiences of individuals with dementia are at the forefront.

Currently psychological service provision in the area of dementia appears to be sporadic, with different areas across the National Health Service (NHS) offering a mixture of services or none at all. Clinical psychologists currently appear to predominate in this area although counselling psychologists also work in the field. This difference is understandable given that counselling psychology is a relatively new profession in the UK (Orlans & Van Scoyoc, 2009). As the numbers of counselling psychologists rise, however, and their roles become increasingly diverse, it can be postulated that the numbers employed in the older adult and dementia field will also grow. Furthermore, it is anticipated that, with the current political agenda in this field being concerned with the increasing numbers of the general population developing dementia and following the advancement of pharmacological treatments, this will give rise to further opportunities for counselling psychologists. Consequently, it is anticipated that this study will be valuable for counselling psychologists in developing and raising awareness of counselling psychology research in the dementia field and informing clinical practice surrounding the experiences of psychotherapy with individuals diagnosed with dementia including therapeutic processes such as the therapeutic relationship.

In considering psychological therapists' position as participants within this study, it could be argued that, given the move towards holding the individual with dementia at the centre of the work and given the existing research emphasising the divergence between client and therapist reporting of the therapeutic relationship, the focus of this research could perhaps have been on the clients' experience. However, it could also be reasoned that focusing on the therapist's experience is equally as important. In particular, as highlighted above, given the aging population and increasingly high incidence of dementia, meaning that more counselling psychologists are likely to be working in the field, it is therefore of value to gain an adequate understanding of what it is like to be a practitioner working in this area in order to further inform this work. Moreover, focusing on the therapists' experience seems to become increasingly important given the challenging nature of the work. Additionally, the evident divergence between client and therapist in terms of perceptions of the therapeutic process and relationship suggests that it is all the more important to explore both groups' experiences separately. These ideas can be considered as very much in line with the emphasis placed in counselling psychology on the subjective experience of the individual regardless of whether this individual is a client or therapist.

2.6 Research Rationale

In the past it was assumed that psychotherapy within the dementia population was not possible. This review has demonstrated that there currently exists a growing evidence base for the use of psychotherapy with individuals diagnosed with dementia. A variety of psychotherapeutic models have been associated with dementia work including cognitive behavioural, humanistic and psychodynamic models (Bender & Cheston, 1997). There has also been an expanse of literature exploring the psychological needs of individuals with dementia (for example, Bartlett & Cheston, 2003; Holst & Hallberg, 2003), adaptations to therapy (see Kasl-Godley & Gatz, 2000; Solomon & Szwabo, 1992), and potential challenges faced when working psychotherapeutically with individuals with dementia (such as, Bartlett & Cheston, 2003; Bender & Cheston, 1997). Less research, however, has focused on the actual subjective experiences of psychotherapists particularly considering what it is like for a psychological therapist, such as a counselling psychologist in working psychotherapeutically with individuals with dementia. Where research does exist it appears to be anecdotal or does not look at psychotherapists' experiences in any depth (for example, Lipinska, 2009; Mosher-Ashley & Witkowski, 1999). Furthermore, none of the research has arisen from counselling psychology research. As counselling psychologists are already working within the dementia field and it is possible that they will do so increasingly in the future, research exploring psychological therapists' experiences of psychotherapy in the area of dementia would be valuable to develop an increased understanding of the work as well as addressing the relative deficiency in counselling psychology literature. Additionally, little research in the area of dementia considers the therapeutic processes involved in the therapeutic work, particularly in relation to gaining an understanding of the therapeutic relationship. As discussed above, this is an essential feature of any therapy and has been associated with positive client change (Lambert & Barley, 2001). Furthermore, the therapeutic relationship is a fundamental aspect of the philosophy of counselling psychology (Strawbridge & Woolfe, 2003). Given these considerations therefore, further research exploring therapeutic processes as experienced by psychological therapists working with individuals with dementia would be important.

Given the dearth of literature outlined in this review regarding the experiences of psychological therapists working psychotherapeutically with individuals with dementia, furthering the knowledge base in this area would be valuable for both counselling and clinical psychologists working in the dementia field. Identifying significant aspects of the work, particularly relating to therapeutic processes, such as the therapeutic relationship, would also be informative for clinical practice. Additionally, the research can help to raise the profile of psychotherapeutic work with individuals diagnosed with dementia for counselling psychologists currently outside the field. Given the increasing numbers of the population being diagnosed with dementia, and the enhancement of pharmacological treatments for this condition, it is likely that a better understanding of working with this client group will become increasingly important for counselling psychologists working in older adult settings. Furthermore, given the current climate with government initiatives such as Improving Access to Psychological Therapies (IAPT), raising awareness of the complexities of working with this client group would have considerable importance. Therefore, it could be argued that although this research does not directly attend to the voice of the individual with dementia, in raising awareness of the work of the therapist, the research might open up channels through which the individual can be empowered and their voice can be heard. Psychological therapists, such as counselling psychologists, come from a unique philosophical and psychological background and are particularly interested in reflecting on the therapeutic processes experienced with clients. As a direct result of this, a strong emphasis is placed upon developing the therapeutic relationship. They are therefore in an advantageous position to be able to offer a valuable contribution to an increased understanding of psychotherapy with individuals with dementia where the current evidence base is limited. Gaining an understanding of the experiences of psychological therapists working within the area of dementia may also be valuable for other professionals such as community psychiatric nurses and care support workers where less formal therapeutic encounters take place.

Given the above rationale, the central research question for this study is: How do psychological therapists experience their psychotherapeutic work with individuals with dementia? Additionally the study aims to answer the following sub-question: How do psychological therapists experience the therapeutic processes involved, such as the therapeutic relationship, when working with individuals with dementia?

3.0 Methodology and Procedures

3.1 Methodology

3.1.1 Research Design and Rationale

A qualitative methodology was employed for this study using semi-structured interview data analysed using Interpretative Phenomenological Analysis (IPA). The rationale for the research design will be explored in detail in the following sections.

3.1.2 Quantitative Vs Qualitative Methods

It has been well established that quantitative methods have taken precedence over qualitative methods in research history (Keegan, 2006). Qualitative methods have only come to the forefront of research methodology in psychology over the last twenty years (Mays & Pope, 2000). This development has been as a result of a recent critique of quantitative approaches which have particularly challenged the positivist ideas associated with these methods (Murray & Chamberlain, 1999). Although some overlap between the two methods, generally quantitative methods are most suitably employed for measuring specific variables or exploring the generality of particular factors whilst qualitative methods are more appropriate for exploratory research (Yardley, 2000). Smith (2008) emphasises that qualitative methods in psychology are often associated with examining, describing and gaining an understanding of an individual's experience. Additionally, emphasis is predominantly placed on developing an insight into the world view of a small group rather than testing a specific hypothesis using an extensive sample.

In considering the main research question for this study, which was concerned with gaining an understanding of how psychological therapists experience their psychotherapeutic work with individuals with dementia, utilising a qualitative method appeared to be most appropriate. A qualitative approach enables the researcher to develop an in-depth study of phenomena, such as psychological therapists' experiences, that are not easily quantifiable. Given that the research question is also exploratory in nature, a qualitative approach lends itself well to this and will allow for the emergence of unanticipated findings (Barker, Pistrang & Elliott, 2002).

3.1.3 Overview of IPA

IPA was developed as a qualitative approach in the mid-1990's (Smith, 1996). IPA has three main theoretical underpinnings in that it is phenomenological, hermeneutic and idiographic in nature (Smith, Flowers & Larkin, 2009). The approach focuses on the detailed lived experience of the individual and how that individual makes sense of their experience (Eatough & Smith, 2008). The phenomenological aspect of IPA has been influenced by key philosophical figures such as Husserl, Heidegger, Merleau-Ponty and Sartre (see Smith et al., 2009, for a description of their work). Phenomenology is concerned with developing an understanding of what the human lived experience is like and how individuals might come to understand or put meaning to their experiences (Smith et al., 2009). Whilst attending to this lived experience, IPA also recognises that meaning-making is contextually bound within a socio-historical framework (Eatough & Smith, 2008). The interpretative aspect of IPA is influenced by hermeneutics, the theory of interpretation. In IPA it is recognised that it is difficult to extract directly the experiences of an individual. Understanding is therefore developed through a process of interpretative engagement (Smith et al., 2009). IPA can therefore be seen as a twofold process in that it is phenomenological, concerned with an individual's lived experience and own perceptions, whilst also being an active process for the researcher who is attempting to understand and interpret the individual's interpretation of their lived experience (Smith & Osborn, 2008). Thus an IPA researcher is considered to be engaged in a double hermeneutic in which they are attempting to make sense of the participant trying to make sense of their own experience (Smith et al., 2009). Additionally, as Smith et al. (2009) have highlighted, a further double hermeneutic exists in IPA in which the researcher adopts both an empathic and questioning stance. The researcher aims to adopt their participant's position and understand what it is like for them, whilst also taking a different more quizzical perspective of their participant. In doing so, the notion of the researcher standing in the participant's shoes whilst also standing alongside their participant is engendered (Smith et al., 2009). Finally, IPA is also idiographic by nature, in that it is committed to exploring in detail the particular instances of lived experience (Smith et al., 2009). In focusing on the particular rather than the universal, knowledge is acquired through understanding meaning as opposed to ascertaining a causal relationship. However, it is argued that, in attending to the particular, generality can be reached through a slow and cautious process of research development (Eatough & Smith, 2008).

3.1.4 Data Collection Methods

In line with the theoretical stance of IPA, data collection methods are required to be flexible and to facilitate the acquisition of data that holds the individuals' experiences and meanings as central (Smith & Eatough, 2006). Consequently, methods such as questionnaires or structured interviews are deemed unsuitable for this type of analysis (Smith & Osborn, 2004). A number of methods of data collection have been identified in IPA studies which enable a researcher to try to enter into the world of the individual. Such approaches include autobiographical accounts, diaries and online interviews. The most widely used method in IPA, and other qualitative methods, is the semi-structured interview (Smith & Eatough, 2006). Semi-structured interviews contain a number of questions, prepared in advance, which are intended to be open in nature so that further questions can follow spontaneously in pursuit of particular lines of enquiry. Considerable preparation is, therefore, required prior to the interviews as well as creativity during the interview process and time to analyse the interview data (Wengraf, 2001). Smith and Osborn (2008) highlighted a number of advantages of employing semi-structured interviews for IPA. In particular, it was suggested that the method enhances rapport and empathy between researcher and participant. Furthermore, the flexibility of the approach enables the researcher to penetrate novel areas and offers the potential for rich data to be gathered. In contrast, however, it was acknowledged that semi-structured interviews can be difficult to control, are time consuming and can be difficult to analyse compared to other methods.

3.1.5 Compatibility with Research Question

IPA was deemed to be an appropriate method of analysis in light of the research question which aimed to explore the subjective experience of psychological therapists working psychotherapeutically with individuals with dementia. The notion of exploring the personal lived experience and meanings of an individual is the central theme of IPA (Smith & Osborn, 2008) and is also consistent with the philosophy of counselling psychology, in which the subjective experience of clients is fundamental (Strawbridge & Woolfe, 2003). Additionally, as the research topic in this study remains an under-researched area and the research question was open in nature, IPA appeared to be the most suitable method of analysis as it has been documented to be valuable when working with complex, novel or process related questions (Smith &

Osborn, 2008). Furthermore, IPA has been utilised in a number of studies into dementia (for example, Clare, 2003; Moniz-Cook, Manthorpe, Carr, Gibson & Vernooij-Dassen 2006; Pearce et al., 2002) and therefore has already demonstrated its value within the field. IPA also has relevance within the context of NHS policy in which the voices of service users and employees are of increasing importance. Thus the approach enables closer links to be established between research and practice (Reid, Flowers & Larkin, 2005).

3.1.6 Epistemological Standpoint

IPA assumes that what individuals report in terms of their thoughts and feelings are linked to their underlying experiences of a particular phenomenon. As a result, IPA can adopt a broadly realist position to knowledge production assuming that a real world exists (Willig, 2001). However, IPA, given its phenomenological underpinning, can also be positioned on a relativist continuum. What is important in IPA is how a particular phenomenon is experienced. Thus reality is shaped according to the individual's view of it (Willig, 2001). IPA can also be placed within a contextual constructionist epistemology assuming that context is significant to an individual's perspective (Lyons, 2007). IPA, though placing emphasis on the personal, has also been influenced by the concepts brought from social constructionism in which social, cultural and historical factors are central to experience and understanding (Eatough & Smith, 2008). In terms of the researcher's own epistemological standpoint, a middle ground has been taken situating the researcher in a position arguing both a realist and relativist position. Instinctively, the researcher has been drawn towards a contextual constructionist position acknowledging the importance of context. As such, it can be argued that reality is continually changing and that knowledge is context specific influenced by the perspective of the perceiver (Lyons, 2007). However, in taking this position, the researcher does not discard outright a critical realist position recognising the links that can be made between the two perspectives in an analytic context. As Madill, Jordan and Shirley (2000) have highlighted, from a contextual constructionist perspective justification for the findings is derived from grounding the data in the accounts. Consequently a move can be observed toward more realist claims emphasising the significance of social realms in our perceptions. The researcher's position will be considered further in the reflexivity section at the end of this chapter.

3.1.7 Reflexivity

As described above, one of the key principles of IPA is the researcher's involvement in a process of interpretative engagement, in which their own stance is accepted to be implicated in the analysis. The researcher is therefore required to take a reflexive position throughout the research process (Willig, 2008). Reflexivity in research terms creates transparency and adds validity to the study, contextualising the data. It can be seen as an interactive process between the researcher, participants and the analysis. Furthermore, it can be seen to create an opening between subjectivity and objectivity enabling exploration of more obscure aspects of experience (Etherington, 2004). Smith et al. (2009) have highlighted that the researcher may not be aware of all their pre-conceptions prior to the analysis and that a cyclical process of reflection and bracketing off or putting to one side any pre-conceptions must take place. Furthermore, reflexivity is a significant aspect of the professional identity of a counselling psychologist (Hammersley, 2003). Thus, throughout this research study, a reflexive process has been assumed by the researcher. Reflexivity will be addressed at the end of the methodology and procedures chapter and will be taken up again at the end of the discussion. The use of first person will be adopted throughout the reflexivity sections in order to remain close to the researcher's personal experiences.

3.1.8 Alternative Methods

Other qualitative methods initially considered but discounted included discourse analysis and grounded theory. Discourse analysis is predominantly concerned with the role of language in the construction of social reality. The method has evolved over the years with different approaches outlined. Two versions have been identified here, discursive psychology and Foucauldian discourse analysis (Willig, 2008). Discursive psychology is particularly concerned with individuals' actions in relation to their talk. Thus the individual plays a key role in the use of discursive strategies to manage interactions. In this context, experience or subjectivity is viewed to be part of a discursive strategy to which an individual may make reference in order to substantiate a claim. In contrast, Foucauldian discourse analysis explores the role and implications of discourse in relation to an individual's culture. Thus, whilst discursive psychology focuses on how individuals use discursive strategies to achieve interpersonal objectives, Foucauldian discourse analysis is concerned with what is constructed through discourse and what the implications of this are for possible ways of being

(Willig, 2008). Although both discourse analysis and IPA identify language as an important factor, IPA argues that an individual's experience reflects their inner world and, therefore, identifies a connection between verbal responses and cognitions. Whereas discourse analysis emphasises the relationship between verbal responses and behaviours (Smith, 1996). As the central tenet of the research question for this study was concerned with exploring the experiences of psychological therapists working psychotherapeutically with individuals with dementia, with a view to understanding their inner world or lived experience, IPA was perceived to be more suitable than discourse analysis for this purpose.

Grounded theory, another qualitative approach, was developed in the 1960's by two sociologists Glaser and Strauss (Charmaz, 2008). The main endeavour in grounded theory is the development of a model illuminating particular relationships or processes derived from the key experience or event being explored. The theory established must develop from the descriptive data rather than be drawn from existing concepts (Chamberlain, 1999). Thus the researcher identifies a broad research area initially and gathers data, developing concepts to make sense of the data in a continual and increasingly sophisticated process of analysis. Grounded theory can be viewed as an inductive method at the outset of data analysis but gradually, as concepts are developed that are grounded in the data, the method is consequently considered to be deductive in nature (Chamberlain, 1999). The main key difference between IPA and grounded theory is that the latter is concerned with developing a universal model of a phenomenon whilst the former offers an account of an individual's experience in relation to a specific phenomenon (Smith et al., 2009). As the research question in this study was specific and was interested in presenting an account of the experiences of psychological therapists in working psychotherapeutically with individuals with dementia, grounded theory was not deemed to be an appropriate method of analysis for the research study.

3.1.9 Validity

Evaluating the quality in qualitative research has been a topic of debate for a number of years now (Mays & Pope, 2000). Central to this debate is the idea that, within qualitative research, different researchers have differing perspectives on reality which are equally valid. This, therefore, raises questions as to which perspective to use when assessing quality in qualitative research. As it is clearly impractical to include every researcher's perspective, the notion of establishing general criteria to assess the validity of qualitative research was developed (Yardley, 2008). A further challenge for evaluating qualitative research is the assumption that quantitative evaluation criteria might also be applied to qualitative research. Yardley (2008), however, highlighted several differences between quantitative and qualitative approaches suggesting that quantitative criteria would be inappropriate for qualitative research. Quantitative research, for example, generally focuses on minimising the influence of the researcher whilst qualitative research acknowledges that the researcher will have an influence on the research. Where quantitative research focuses on reliability and standardisation, qualitative research is interested in context and difference. Finally, whilst quantitative research aims to generalise to the wider population, qualitative research focuses more on the contextual process and hopes to provide useful insight for other similar contexts.

As Smith et al. (2009) advocate the use of Yardley's (2000; 2008) criteria for assessing qualitative research, these have been considered here in the light of this research study. Yardley (2000) highlighted four fundamental principles to consider when assessing validity in qualitative research. The first principle, sensitivity to context, emphasises the importance of drawing on relevant theoretical and empirical literature and showing sensitivity towards the perspective and socio-cultural context of participants at all stages of the research process. Sensitivity can be observed in this study in a number of ways. As Smith et al. (2009) have suggested, in choosing IPA as the methodology for this study, sensitivity has been demonstrated through engaging closely with the individual in context. Through the recruitment process, described below, the researcher was required to negotiate access to the participant sample, thus a continual process of engagement was required from the outset of the study. Highlighting relevant research literature, and in particular drawing on other qualitative research, the researcher has remained sensitive to the context in which the study is situated. Sensitivity was also shown during the interview process through encouraging participants to narrate significant aspects of their experience using open ended questions and in the researcher adopting an empathic stance towards participants during the interviews. Finally, during the analytic process, the researcher tried to remain sensitive to the data by systematically working through each account and grounding interpretations in the raw material through the use of verbatim extracts. The second criteria suggested by Yardley (2000), is that a research study should be able to demonstrate commitment and rigour. In IPA, commitment can be shown through adequately attending to the participant through the interview process and in investing fully in the analytic process (Smith et al., 2009). During the data collection and analytic process in this study, the researcher endeavoured to keep these aspects of commitment in mind, where possible, attending closely to what each participant was articulating. Rigour concerns the thoroughness of the study in terms of the sample employed in relation to the research question, quality of the interview and the care taken over the analysis (Smith et al., 2009). In this study, the sample was homogeneous and was selected in order to adequately address the research question. In depth interviews were conducted with participants which aimed to probe into their experience sufficiently where appropriate. As described above, the analytic process was systematic and the researcher tried to be sufficiently interpretative, adequately representing each participant's account through the verbatim extracts. Thirdly, Yardley (2000) emphasised the importance of transparency and coherence throughout the research process. The researcher has attempted to enhance transparency and coherence in this study through providing a detailed account of the research process, providing a clear audit trail evidencing the analytic process and through an ongoing process of reflexivity. The audit trail was also independently followed by an academic peer. Finally, validity can be assessed in terms of the impact and importance of the study (Yardley, 2000). This aspect will be evaluated fully in the concluding chapter.

3.2 Procedures

3.2.1 Sampling and Participants

3.2.1.1 Sampling

Purposive sampling was employed to select participants for the research study. This enabled the researcher to locate a discrete group that would be suitable in addressing the research question for the study and to maintain a homogenous sample, ensuring a richness of data. Remaining constant with a qualitative approach, purposive homogenous sampling was the most appropriate method in order to develop insight into the particular experience of focus and to ensure that the research question was meaningful to the participants selected (Smith et al., 2009). In line with other IPA studies and the idiographic nature of IPA, this study had a small sample of nine participants, including the pilot study. A small sample enables the researcher to do justice to the individual's experience and will enable a depth of analysis, thus avoiding obtaining a superficial analysis (Smith & Eatough, 2006). This number was also deemed appropriate by the researcher given that the research study formed a doctoral level thesis and that the research process is time consuming.

3.2.1.2 Inclusion / exclusion criteria

In order to ensure as great homogeneity as possible within the sample selected, without considerably reducing the chances of recruiting participants, the following inclusion and exclusion criteria were employed. Participants were required to be qualified psychological therapists, such as counselling or clinical psychologists. They were also required to have been working psychotherapeutically in an older adult setting with older adults (aged 65 years old and above) diagnosed with dementia of the Alzheimer's type and to have at least one year's experience in this role. In keeping the sample as consistent as possible, in terms of participants' level of qualification, psychological background and experience of this particular client group, it was anticipated that it would be possible to develop insight into the particular phenomenon in question and to explore variability within the group. In selecting participants with at least one year of experience, it was hoped that they would have sufficient familiarity with the topic of interest to be able to speak in depth about their experiences. Furthermore, in order to keep the sample as homogenous as possible, the focus was placed on participants' experience of their clinical work with individuals with Alzheimer's disease rather than dementia more generally. Practice in any psychotherapeutic model was deemed acceptable given that often psychological therapists utilise a range of approaches in their practice. Any practitioner who had been working away from the field of dementia for any considerable length of time, for example more than a few years, were excluded from the study. Again this was in order to ensure that participants had sufficient familiarity within the area to address the research question and to have consistency in the sample.

3.2.1.3 Recruitment

Prior to recruitment, the relevant ethical permission had been sought and granted (see ethics section below). Participants were obtained via a number of different recruitment strategies. A brief advertisement was displayed in the notices section of the BPS Psychologist magazine requesting psychological therapists to contact the researcher, via email, to express their interest in the research. Psychologists listed on the BPS main society website with an interest in dementia were emailed directly by the researcher with the recruitment poster (appendix one). The recruitment poster was also sent via email to each of the regional leads of the Psychology Special Interest Group for older adults (PSIGE) and was subsequently dispersed to PSIGE members. A positive response was received from individuals showing an interest in participating in the study. Individuals registering their interest were sent details of the study via email including the information sheet (appendix two) and inclusion/exclusion criteria and were requested to contact the researcher if they fitted the study criteria and wished to take part in the study. Once individuals had agreed to take part, Research and Development approval was sought from the participant's NHS trust where necessary. Once approval had been granted the participant was contacted by the researcher and arrangements were made for the interview. The time between agreeing to take part and completion of the interview varied across participants between approximately one month and six months depending on the approval process for the particular NHS trust. In total, participants were recruited from five different NHS trusts across London and the South-East of England, with one participant working privately forming the initial pilot study.

3.2.1.4 Participant demographics

The demographics for each of the nine participants are outlined below. Pseudonyms have been used to preserve confidentiality for each participant. All nine of the participants were White British aged between 35 and 65 years old.

Table One. Participant Demographics

Participant Name	Relevant experience of working in dementia field	Theoretical Orientation outlined in account
Brenda	BPS chartered clinical & neuro psychologist – 20 years experience.	CBT / Person-centred
Rebecca	BPS chartered clinical psychologist – five and a half years experience.	CBT / Cognitive Analytic Therapy / Systemic
Margaret	BPS chartered consultant clinical psychologist – 19 years experience.	CBT / Narrative
Sophie	BPS chartered clinical psychologist – seven years experience.	Did not specify particular orientation
Richard	BPS chartered consultant clinical psychologist – 15 years experience.	Eclectic
Julia	BPS chartered clinical and counselling psychologist – Over five years experience.	Did not specify particular orientation
Sian	BPS chartered clinical psychologist – Five and a half years experience.	Person-centred
Mary	BPS chartered clinical psychologist – Three and a half years experience.	Cognitive Analytic Therapy / Life Review
Kerry	BPS chartered clinical psychologist – Seven years experience.	Cognitive Analytic Therapy / CBT

3.2.2 Materials

The materials utilised in the study are listed below:

- Recruitment poster
- Participant information sheet
- Participant consent form (appendix three)
- Information sheet listing support organisations (appendix four)
- Digital recorder
- Interview room located in approved NHS premises / university premises
- Interview schedule (appendix five)
- Reflective diary (see appendix six for example extract)

3.2.3 Interview Schedule

The interview schedule consisted of six open ended questions aimed to address the main research question regarding the experiences of psychological therapists working psychotherapeutically with individuals with dementia. It was developed using a funnelling approach beginning with more general questions to enable the development of rapport, so that the participant felt at ease, followed by more significant questions. To get to this point, the researcher went through a sifting process of possible questions, discarding questions that might be deemed closed or that perhaps did not address the research question adequately, until a satisfactory stage was reached. The interview schedule was also discussed with the researcher's academic supervisor prior to the pilot stage. The interview schedule was used as a guide for the interview and the questions were used flexibly with each participant. Having a flexible structure to the interview schedule allowed participants to set the parameters of the discussion and enabled the researcher to follow up more novel areas as they arose. Smith and Eatough (2006) emphasise that the aim of the interview in IPA is to be participant led enabling the participant's narratives to develop. This was, therefore, the aim of the interviews in this research study.

3.2.4 Pilot study

Within the pilot phase of the study, the researcher gathered data from a single participant using a semi-structured interview. This provided the opportunity to test the interview schedule and to examine the data gathered. The interview was transcribed and a brief analysis of the data was completed, identifying promising themes. The interview questions and analysis were subsequently discussed with the researcher's academic supervisor. Following the pilot study only minor amendments were made to the wording of questions in the interview schedule. It should be noted here that due to the richness of data gathered in the pilot interview, and given that all other procedural and ethical considerations were the same as for subsequent participants, the data from the pilot has been included in the analysis.

3.2.5 Interview process

At the beginning of each interview, the researcher discussed the information sheet and consent form with the participant, giving ample opportunity to ask questions, and fully informed signed consent was acquired. Each interview lasted between approximately 35 and 80 minutes and was digitally recorded. The same semi-structured interview schedule was used for each participant, although there was some variation in the order of questions asked and prompts used, depending on the participant's responses given. As discussed below, each participant was fully debriefed after the interview and was offered an information sheet listing support organisations which the majority accepted. Immediately after each interview the researcher made some notes about the interview in a reflective diary to assist in the analytic process and with researcher reflexivity.

3.2.6 Ethical Considerations

3.2.6.1 Ethical approval

Ethical approval for the research study was initially granted by London Metropolitan University ethics panel and research degrees committee. As the research study predominantly involved interviewing participants who worked in the NHS and who may have been discussing their confidential client work further ethical approval was also required from the NHS. As a necessary requirement for the NHS ethical process, prior to submitting the application for ethical approval, an NHS trust sponsor was sought. Sponsorship was subsequently agreed with the researcher's local older adult psychology department and Research and Development office at Oxleas NHS Foundation Trust. Following this, the application was submitted and the Brent Medical Ethics Committee met on 27th July 2009 to review the study. A favourable opinion was put forward subject to the following conditions:

- Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.
- To confirm the name of the second researcher (as described in validity section above and analytic process section below) and to provide their curriculum vitae for the records.
- Provide an up to date indemnity insurance certificate.
- As a maximum of 12 participants were expected to take part in the research study it would be good practice to allow the participants to review the quotations before publication.
- Data to be stored on an encrypted personal computer.

Please see appendix seven for copy of NHS ethical approval letter. The relevant documents additionally requested were provided to the committee co-ordinator (see appendix eight for receipt confirmation letter) and the other conditions were adhered to in the study. Once participants had been identified for the study, Research and Development Approval for the relevant NHS trusts was applied for and approval received before commencement of the interviews (see appendices 9.1-9.5 for confirmation letters).

3.2.6.2 Participant welfare

3.2.6.2.1 Briefing and informed consent

Potential participants were given the information sheet before they agreed to take part in the study allowing them to give fully informed consent. The information sheet outlined the purpose of the research, what was involved if participants decided to take part, and confidentiality issues, as described in the confidentiality section below. It also emphasised that participants could withdraw from the study at any time without giving a reason. Potential participants were also given the opportunity to ask further questions before they made a decision as to whether they wished to take part. Before the interviews commenced the researcher discussed the information sheet with each participant again. The consent form was then explained reinforcing the key aspects of the information sheet, and participants were requested to provide signed consent before the interviews commenced. By employing an information sheet and consent form it was anticipated that participants would be completely briefed about the research study and that they would be able to provide fully informed consent.

3.2.6.2.2 Debriefing

Participants were given the opportunity to discuss any concerns or feelings evoked during the study, to ask any questions and/or provide feedback. The contact details of the researcher and supervisor were made available to each participant if required at a later date. Participants were also offered an information sheet which the majority accepted. This provided relevant help or supports such as the BPS or Samaritans.

3.2.6.2.3 Confidentiality / anonymity

Personal details and information provided by the participants throughout the research process about themselves or the organisations they worked for remained confidential at all times. Transcripts were made anonymous using pseudonyms and other identifying material was altered. Data was stored on an encrypted computer and identifying material, such as the signed consent forms, were stored in a locked cabinet separate from the transcripts. The key to the cabinet was also stored safely. All material remained in the possession of the researcher at all times. As the data was being collected as part of the researcher's doctoral thesis, it was emphasised to participants that the information, though remaining anonymous, would be shared with academic tutors and markers with the potential for the research study to be published. It was also highlighted that the data would be required to be kept by the university for up to five years and that after this time it would be securely destroyed. Participants were also made aware, before commencing with the study, that the researcher was working within the BPS ethics code of conduct (Ethics Committee of the BPS, 2009). Should information be disclosed by any participant relating to illegal activity or harm to self or others the researcher would be obliged to share this information with a third party.

3.2.6.3 Researcher declaration

The researcher did not have any relationship with the organisations or participants involved in the research prior to the commencement of the study.

3.2.7 Analytic Process

After each interview the digitally recorded data was transcribed verbatim by the researcher. As described above, however, all identifying information was removed from the transcripts. Margins were left either side of the transcript in order to make notes during the analytic process.

The aim of the analytic process is for the researcher to completely immerse themselves in the data and engage in an interpretative relationship with the participants' accounts in order to obtain meanings about the particular phenomenon in question (Smith & Osborn, 2008). In this research study, this process was achieved through a number of stages. Given the idiographic commitment of IPA (Smith et al., 2009), each transcript was analysed case by case working towards a more generalised position. The first transcript was therefore read several times making notes in the left hand margin concerning anything interesting or significant. Smith and Eatough (2006) emphasised that this process enables the researcher to gain a comprehensive view of the data in order that successive interpretations can remain true to the participant's account. Following this stage, emerging themes were subsequently identified and recorded in the right hand margin of the transcript. Smith, Jarman and Osborn (1999), highlight that these emerging themes should encapsulate the essential quality of what is observed in the text. This part of the analysis is also regarded as being at a higher level of abstraction, often drawing upon psychological ideas or concepts (Smith & Eatough, 2006). The emerging theme titles were subsequently listed separately and connections were made between them forming clusters or superordinate themes. Throughout this process, the researcher frequently checked back to the original data in order to stay true to the participant's accounts. In doing so, the researcher is making sense of the data through personal interpretation whilst consistently referring back to what the participant actually said (Smith & Osborn, 2008). At this stage, themes considered inappropriate to the emerging structure or where there was limited evidence for them in the participant's account were discarded. A master list of themes was then developed and identifiers from the transcript were recorded next to each theme in order to remain close to the participant's account and to ensure transparency. The same process was then employed to analyse the other transcripts until an overall list of themes for all transcripts was developed. During this latter process, the researcher was careful to ensure that for each transcript, any new themes emerging were considered in light of the previous transcripts. The final table of themes was subsequently developed into a narrative account outlined in the analysis chapter.

In order to enhance the validity of the analysis, a second researcher independently followed the audit trail from the raw data through to the final table of themes and interpretations ensuring that the trail was transparent and coherent. To maintain transparency, evidence has been provided in the appendices of one full annotated transcript (appendix ten), master theme table for the same transcript (appendix eleven) and the cross case master table of themes (appendix twelve).

3.2.8 Reflexivity

In this section, I aim to situate myself in the research reflecting on what experiences and beliefs I might have brought to the research process that may have shaped the findings that have emerged.

I am a 29 year old White British female who grew up in a middle class area in the south-east of England. I am currently a trainee counselling psychologist in my final year of training for the professional doctorate in counselling psychology at London Metropolitan University. From an early age, I have had an interest in psychology and consequently much of my professional experience has been shaped towards this. My interest in older adult psychology began during my undergraduate psychology degree ten years ago, when I worked part time as a home care assistant. This included working with older adults diagnosed with dementia. In 2006, I completed a Masters of Science in Rehabilitation Psychology at Nottingham University. This had both a large neuropsychological and health psychology focus, considering the psychology of degenerative diseases, brain injury, chronic illness and disability. I later went on to work full time as an assistant psychologist in an older adult community mental health team. This included working with individuals with dementia, predominantly in a diagnostic capacity, but also working therapeutically in a day care service. These experiences really strengthened my enthusiasm for older adult psychology work and raised my awareness of dementia. Consequently, these experiences were a significant factor in my decision to begin research in the dementia field. As part of the M-level component for the doctorate, I completed a qualitative dissertation exploring the experiences of younger people with dementia. One observation resulting from this research was the importance of psychological support for individuals with dementia and this stimulated my interest in researching this area. Aware of the difficulties in recruiting a vulnerable population within a sensitive area such as experiences of therapy, I made the decision to examine psychological therapists' experiences of psychotherapy with individuals with dementia, an area little examined previously. Reflecting on a personal level, my grandparents have also been a significant influence in my life from an early age. This influence strengthened my sensibilities toward older people and influenced my professional decision making towards this field. Dementia as a condition has also been very familiar to me on a personal level from an early age. My late maternal great aunt was diagnosed with Alzheimer's disease during my childhood and more recently my late maternal grandmother was diagnosed with a mixed dementia. These experiences have further cultivated my interest in the dementia field.

My experiences through counselling psychology training, heavily influenced by the philosophy of counselling psychology, have led me to move away from a positivist position which I held prior to training to a more contextual constructionist position to which I currently subscribe. Previously holding a conceivably narrow perception of reality, my current position maintains that knowledge is perhaps context specific and influenced by the perspective of the observer. Reflecting on my theoretical orientation, I would consider myself to be predominantly integrative, recognising the importance of a wide range of models on my thinking including, humanistic, cognitive-behavioural, psychodynamic, systemic, existential and constructivist approaches. Responding to the pressures to adhere to an evidence-based practice model and tensions between the dominant positivist perspective and the more humanistic values of counselling psychology (Orlans & Van Scoyac, 2009), I would also place myself within a reflective scientist-practitioner framework. As such, I attempt to maintain a balance between remaining true to my personal philosophy of counselling psychology whilst retaining an open critical reflective position when considering empirical evidence. Within this framework, I am in agreement with Corrie and Callahan (2000) and Fairfax (2008) in emphasising that the evidence-base must include different approaches, including relational and process research, as well as quantitative methodologies. I believe that this study therefore reflects these ideas.

Having outlined my own pre-existing experience and beliefs I will now move on to reflect upon my own experience of the research process. Prior to commencing the research, I considered myself to know relatively little about psychotherapeutic work with individuals with dementia or what psychological therapists might experience in their dementia work. This enabled me to remain close to the participants' experience and maintain a curiosity without my own views or experiences influencing my interpretations. Despite this, as outlined above, I entered the research process with some pre-conceived ideas based on my previous experiences and beliefs. Consequently, prior to commencing with the data collection I tried to acknowledge these pre-suppositions and bracket them where possible. Through the research process, a number of pre-conceptions became apparent and which initially, I was not aware of which may have influenced the direction of my research in terms of the research question, interview process and analytic interpretations. In particular, I held the assumption that the therapeutic work, including the process and relationship in therapy, with individuals with dementia would be different from working with other client populations. Perhaps with my more positivist tendencies re-surfacing, I placed emphasis in my thinking around participants' experiences of individual psychological models and *doing psychotherapy* with individuals with dementia as opposed to considering a more holistic approach to care. I also made the assumption that the experience of working psychotherapeutically with individuals with Alzheimer's disease would be different to other forms of dementia. During the early stages of forming my research question, I made enquiries with the majority of NHS older adult services across London to assess the feasibility of the study. In doing so, I became aware of the variety of psychological services available for individuals with dementia and the pressures associated with funding services. Additionally, through the NHS ethical process, which was both challenging and frustrating, I became aware of some of the struggles of working in the NHS. Consequently, these fore-understandings may have shaped the way in which I developed my research questions and interview schedule and perhaps influenced my interpretations during the analytic process.

Reflecting on the interview process, a number of interesting aspects came to light. Firstly, my position as a trainee counselling psychologist may have influenced what participants conveyed during their interviews. Several of the participants supervised trainees or lectured students in their work, and at times, I observed that these participants took on an educative stance during the interview. Whilst, as will become apparent in the analysis chapter, participants seemed to value generating awareness about their work, it could be that my influence as a trainee was significant whereas perhaps an interviewer of a similar professional level to participants would receive a different response. For one participant, Margaret, my position as a counselling psychologist seemed to be significant, perhaps influencing her responses during the interview. Having reflected on the language used when developing my interview schedule, I had made the assumption that participants would share a similar psychological language to me. Margaret, however, made a number of references in her interview to the language used in the questions as being different to her own and she seemed to hold assumptions as to how I might practice. Therefore, I wondered whether this might relate to her understanding of the role of counselling psychologists. It is also interesting to reflect on my skills as a researcher in carrying out the interviews. Being aware that the researcher's role in an interview is different to a clinician's role and wanting to maintain an open stance, I was cautious at times in how I followed up interesting areas. This was a difficult balance in which, at times, my preoccupation perhaps led to missed opportunities for depth. Though this was a skill that I believe did develop during the data collection process, it was compounded by having a long gap between some of the interviews. Conversely, the gaps between interviews enabled me to begin the majority of interviews with a relatively open mind to what the participant might bring. Methodological considerations will be explored further in the concluding chapter.

During the analytic process, I found it difficult at times to attend to each case in its own right, already influenced by the earlier interviews. During the analysis of the pilot study, I was struck by the language used by the participant, Brenda, seemingly referencing the idea of threat. Consequently when analysing the other participants' transcripts, it became difficult to bracket this idea. This may, therefore, have influenced my interpretations of the successive narratives. In order for my reflections on the analytic process to have further meaning for the reader, I will continue this reflexivity at the end of the concluding chapter.

I believe it important to acknowledge that my personal experiences, values and ideas have influenced this research throughout the whole process. Nonetheless, I believe that

I have been suitably transparent in my analysis to ensure that my findings are grounded firmly in the participants' accounts and are not as a result of my pre-conceptions.

4.0 Results

4.1 Introduction

This section presents the results of an interpretative phenomenological analysis (IPA) of nine psychological therapists' experiences of working psychotherapeutically with individuals with Alzheimer's disease. During the data analysis, themes were identified from the transcribed data that were continuously ordered and reordered within a developing thematic hierarchy. Initially, over 100 themes emerged which were organised into 31 thematic groups and subsequently were organised under the following three super-ordinate themes representative of the participants' subjective experiences as perceived by the researcher: **Considering the Psychotherapeutic Work; Bridging between Two Worlds; and The Detrimental Effect of Dementia on the Therapist and the Therapeutic Work.**

These super-ordinate themes and corresponding sub-themes are presented in Table two below.

Table Two. Summary of Super-ordinate Themes and Sub-themes Arising from Participants' Accounts

Super-Ordinate Themes	Sub-themes
Considering the Psychotherapeutic Work	Assuming a Diverse Approach
	Defending the Validity of the Psychotherapeutic Work through Ambivalence and Uncertainty
	Therapist Motivations and Values
Bridging between Two Worlds	Understanding the Client's World
	Supporting the Client's Emotional and Psychological World
	Making a Connection with the Individual
The Detrimental Effect of Dementia on the Therapist and the Therapeutic Work	Personal Impact
	Swimming against the Tide
	Those Groundhog Day Moments

Smith (2004) has emphasised that, in IPA, analysis should be grounded within the text in which the data is from and that the researcher should move beyond the text to a deeper level of interpretation. Within this section, each super-ordinate theme and corresponding sub-themes will be described in turn and interpretations of the participants' narratives will be explored and firmly grounded in the data through the use of verbatim extracts from the transcripts to illustrate and support those interpretations. It is recognised that the interpretations are only one possible subjective account of the participants' experience and other researchers may have focused on different aspects. Additionally, the themes identified were selected due to their relevance to the research questions and so may not cover every possible aspect of the participants' experience. Whilst the themes identified were common to all accounts, there were also areas of divergence and difference which have been explored where relevant. Overlap was evident at times between the super-ordinate and sub-themes which has been indicated where appropriate. The concept of identity and existential ideas appeared to traverse all themes in the analysis. These concepts will therefore be explored in each theme as they arise and will be considered at the end of this section.

What was apparent throughout the transcripts was that participants found it difficult to differentiate between their experiences of working with clients with Alzheimer's disease and other forms of dementia. Thus they seemed to use the label Alzheimer's disease and dementia interchangeably. Consequently throughout the analysis section it seemed more appropriate to use the term dementia in line with participants own experiences. Additionally, the word 'client' and phrase 'individual with dementia' have been used interchangeably and the term 'work' has been employed to refer to 'psychotherapy with individuals with dementia' to ensure clarity for the reader.

In order to be succinct, throughout the verbatim extracts, the omission of irrelevant material in quotations is indicated using empty square brackets. Ellipses are used to indicate pauses in the flow of participants' speech, for example '...' would indicate a pause of three seconds. For ease of reading, repeated words or utterances, such as 'um', have been omitted unless relevant. Pseudonyms for each participant have been applied throughout the analysis to protect anonymity and any other identifying information has been removed. The use of present tense will be employed throughout the remainder of this section in order to stay more closely connected to the participants' experiences.

4.2 Considering the Psychotherapeutic Work

All of the participants reflect on their psychotherapeutic work with their clients diagnosed with dementia. It is apparent in participants' narratives that they make use of a range of psychological models in their practice and often seem to adapt their practice for the client group. They also appear to reflect upon their work displaying ambiguity as to its value and uncertainty surrounding the differences and similarities in their work. Furthermore, participants describe their experiences of what has driven them to work in the dementia field and what motivates them to continue with the work. These aspects are explored further in the sub-themes below.

4.2.1 Assuming a Diverse Approach

There is considerable variation as to the type of psychological model participants draw on in their practice and their approach to their work with clients. This diversity will be explored further in this sub-theme.

For some participants, particular psychological models may be helpful in their work and they reflect upon the fit of these models to dementia in their accounts. Rebecca, for example, outlined the importance of a basic Cognitive Behavioural Therapy (CBT) formulation in her work. This formulation is perhaps important to Rebecca in order to guide her work with her clients:

Rebecca "*So that does fit sort of with often with CBT I guess quite well. So you might be looking for, you know, what's the presenting difficulty, is that being maintained by behaviours or thoughts or feelings and then I guess individual work would be based on that*" [4, 190].

In contrast, Margaret highlights how well a narrative approach fits into her work with clients. She perceives a narrative approach to be particularly suitable when working with older people due to them often having interesting stories to tell:

Margaret "*The other approach which is almost intermediate, which I think fits older people with dementia very well, is using a narrative approach. [] Working with their stories is fascinating and that ties in with older people as well because older people have wonderful stories*" [3,112].

For these participants, it might be important to identify particular approaches that suit the client group they are working with. For the majority of participants however, what appears to be significant is the need to be flexible in the use of the psychological models employed or be adaptable in their approach to the work. Some participants highlight specific psychological therapies which they employ in their practice but adapt according to the client population. Richard considers, in his account, his use of CBT with the client group and need to adapt this approach in order to accommodate his clients' memory difficulties:

Richard "*If I think about it with an old fashioned CBT way of doing things, then of course people aren't going to do their homework because they're not going to remember what it is that I've asked them to do. So it's.. so then you have to think about ways of how you can adapt that and how you can build memory aids into.. into the programme*" [5, 213].

Kerry, in contrast, describes in her account how she finds it beneficial to use aspects of Cognitive Analytic Therapy (CAT) in her work:

Kerry "*I'm not saying that with the sort of people that I've seen who have dementia I've done a full blown CAT therapy, I haven't.. but using elements of it to think about the themes of their life and the themes of their relationships..*" [4, 172].

A number of participants also draw attention in their accounts to the use of tools, such as written aids, to assist their clients in remembering the sessions. Julia outlines her experience of making minor adjustments in therapy in the form of written notes or diagrams to aid her clients' memories:

Julia "*It's not a great deal of alteration that's needed to the therapy really. I mean just using sort of notes in sessions and diagrams and things is you know quite enough to help people remember from session to session*" [4, 199].

By employing written aids, participants seem to act as a container for their clients enabling them to hold on to their clients' memories of the therapy and aspects of their lives which otherwise would perhaps be forgotten by them.

Participants also express a degree of flexibility in terms of the length of sessions, the time between sessions and the ending of therapy. There does not appear to be any specific archetype for the timings of sessions with participants working flexibly according to the individual client needs. Brenda describes her flexible approach to the interval between therapy sessions in the following extract:

Brenda ".. *the therapy itself was much more intense.. and people sometimes needed shorter times between sessions or sometimes they needed longer time between sessions because they needed more exposure of the exercise..*" [3, 115].

For Brenda, the demand to work in a flexible way perhaps leads her to experience her work with clients with dementia as more intense and difficult than with other client groups. The difficult aspects of the work will be explored further in the super-ordinate theme 'The Detrimental Effect of Dementia on the Therapist and the Therapeutic Work'.

Whilst some participants can be observed to focus on specific models, in other accounts participants intimate the need to develop skills in several psychological approaches in order to be able to work flexibly and to maximise the benefits for their clients. Again Brenda provides a useful explanation of this mixed approach to the work:

Brenda "*So it's adapting, adaptation is the name of the game. Where you start with the behavioural.. approach you might end up with an existential approach or you might end up with a client centred approach*" [9, 438].

Brenda's use of the word "game" is interesting in this extract. Whilst Brenda is perhaps highlighting here that adaptation is her goal in the work, it could also be interpreted that there is a competitive element to her work. In this "game" she is perhaps grappling with the challenges that her clients' difficulties might present and in doing so finds herself moving between different psychological approaches. Taking the analogy of a chess game it could be interpreted that these approaches are like chess pieces which Brenda moves between to maximise her strength in order to win the game. This is one strategy that can perhaps be observed in her account in response to the difficult aspects of dementia. Further strategies will be remarked upon throughout the analytic process.

Coming from a person-centred tradition, Sian gives the impression that she views her work as encapsulating a whole approach to care in which any interaction is suggested to be a therapeutic encounter. This experience contrasts to the majority of participants who focus more on individual one to one work in their accounts drawing on a specific model at a particular time:

Sian "*What my idea of, you know, psychological therapy and therapeutic work with people with dementia is sort of beyond that kind of one to one session, and like I say I see walking down the corridor and speaking with someone for ten minutes, or five minutes, or 30 seconds as a potential therapeutic encounter if you like*" [8, 366].

Overall, what is apparent from the accounts is that there are striking commonalities between participants' experiences in terms of the flexible way in which they practise and their exploration of this diversity within the interviews. What seems to be particularly important to participants is being able to identify with a certain approach or define their practise in a certain way. Given the difficult nature of the work and uncertainty that the work may generate, which will be explored in later themes, it could be interpreted that developing and holding on to a specific identity as a therapist when working with individuals with dementia is significant to participants in overcoming these difficulties. This is one way in which the theme of identity is apparent within the participants' accounts.

4.2.2 Defending the Validity of the Psychotherapeutic Work through Ambivalence and Uncertainty

Throughout participants' accounts it could be claimed that they spend time evaluating and reflecting upon their work. In doing so, they perhaps experience some ambivalence as to whether or not psychotherapy with individuals with dementia is valuable. They also appear to experience uncertainty as to whether this work is any different to working with individuals without a dementia diagnosis, exploring this question in their accounts. These aspects will be considered in this sub-theme.

The majority of participants emphasise in their accounts the importance of the psychotherapeutic work and endorse the work where possible. Validation and justification for the work is evident in the following statement spoken by Brenda:

Brenda "*It's not the label that matters, it's the process people go through and the help they need with it. Nobody actually denies a person with dementia the right to use the toilet on time, so they should actually have the right to use an outlet for their emotions on time as well!*" [18, 885].

In this extract it can be observed that Brenda experiences a tension between the practical needs of the individual with dementia, such as using the toilet, and the more existential needs, such as providing a channel for emotions. She highlights the importance of the latter to support her clients through the adjustment process and to ensure their rights as individuals are not lost. This existential theme is evident throughout the analysis and will be returned to in later sub-themes.

At the same time as validating their work, paradoxically participants can be seen to question the benefits of working psychotherapeutically with individuals with dementia, and express doubt as to whether it is helpful. Rebecca, for example, questions whether therapy is helpful and suggests that other services might be more appropriate to support these clients:

Rebecca "*I suppose then on the other hand there's another issue about whether it might be pathologising actually to see people and whether actually linking in people with non-NHS service, so the Alzheimer's Society and local day centres, where there's sort of maybe not quite so intensive psychological interventions, but there's still I guess quite a lot of active listening and psychological work, whether maybe that is better for people [clears throat]*" [3,143].

This extract seems to contradict her quotation in the previous sub-theme in which she speaks about the value of CBT in the work. Rebecca is also quite tentative here as evident in her use of the words "suppose", "might", "sort of maybe" and "I guess". Moreover she clears her throat after speaking suggesting that what she says does not sit entirely comfortably with her. Just prior to this extract, Rebecca was speaking about the pressure she feels to keep the waiting list down and moving her clients on. It could be postulated that her questioning of the value of the therapy may be as a result of this tension.

Kerry also questions whether psychologists need to do the work or whether other professionals could adequately complete it:

Kerry "*I think its right to have arguments about whether or not a psychologist needs to do that work, whether or not that's work that can be done by.... other health professions*" [4, 196].

In both these examples, there is some suggestion that the work is not 'proper' therapeutic work given that other professionals without psychological training might be suitably able to complete it. Margaret perhaps supports this interpretation in the following extract:

Margaret "*..for some people the engagement in therapy is by seeing you and the more immediate value of coming whereas actually the real therapy is a more sort of profound change and people with Alzheimer's can actually lose that longer term vision of things*" [10, 484].

It is evident in this extract that Margaret, in line with Kerry and Rebecca above, suggests that 'proper' therapy is lost on individuals with Alzheimer's disease who she perceives cannot make "profound change". One interpretation of this opposition to therapy could be that for all three participants this acts as a protective mechanism for them. As suggested above, for Rebecca this is perhaps a response to the external pressures she is experiencing in the work. At the time of Kerry's interview, she was due to leave her post and move out of the country. Therefore her reflections upon the value of the work could be a process of adjustment for her and a way of reassuring herself that there will be other professionals to take up the work following her departure. In contrast, Margaret focuses on the lack of change in therapy for individuals with dementia. Thus it could be that thinking that the therapy is not "real therapy" might be comforting for Margaret and take away the pressures she might be feeling to achieve positive change.

It could be considered that one aspect driving participants' uncertainty as to the benefits of psychotherapy with individuals diagnosed with dementia is the perceived lack of a consistent structure or pathway for the work. Participants appear to perceive themselves to be working in relatively unknown territory with limited guidance from research and without a strong evidence-base. A sense of there being a long way to go before these aspects would be in place was apparent in the accounts and Margaret again illustrates this aspect as she highlights the need for further research in order to support and provide direction for the work:

Margaret "*I think it's really the next stage of major research really and.., both getting more sort of case examples, but also you know building a coherent model of how you do it*" [11, 548].

In contrast to Margaret, it can be assumed from Richard's account that he has found the theoretical structure that he needs in order to continue with the work and to cast doubt aside. He reflects on his early career in which he had focused on working with carers of individuals with dementia, rather than the individuals themselves, believing that psychotherapeutic work with the individual with dementia was not possible. In describing this he expresses some regret with regards to his actions, reflecting on times when he could have done more to assist his clients with dementia. He identifies the work of Tom Kitwood and person-centred approaches as a turning point for him in providing him with the foundations on which to base his work:

Richard "*It's kind of giving the theoretical framework if you like for whatever we're trying to do in a way, and then it's giving me the kind of, it's given us the language to talk about it in [laughs]*" [3, 110].

Having a framework for the work and having a solid client case example perhaps provides Richard with the conviction he requires in order to defend the validity of the work despite the uncertainty created by it. Similarly to Richard, Mary describes how she is now willing to keep doing the work given the positive outcomes she has observed whereas previously she seemed to hold doubt about the benefits of the work:

Mary "*I feel really strongly about it now and my, like I said had the group been.. rubbish or had we not seen any changes or.. the one to one work we do with various people with dementia, if we weren't getting the outcomes... then we would obviously not continue to do it but I think from my point of view our outcomes are really good and.. yeah I'll keep on doing the work*" [5, 250].

It could be said that there is a fine line for Mary, and perhaps other participants, in terms of whether they would continue with the work and it can be seen, particularly in her account that this is largely motivated by attaining positive outcomes in the therapy. Understandably, where participants have experienced successful outcomes it could be perceived that there is less uncertainty as to the validity of the work. Whilst for those participants who have not experienced such positive outcomes, or have completed less psychotherapeutic work, there is possibly more of a doubt about the benefits of that work. Thus the variability in outcomes might explain some of the ambivalence experienced by participants. This could also be linked to the ongoing theme of identity. It could be interpreted that positive outcomes in therapy might increase participants' sense of self as a therapist. Additionally, a stronger sense of identity as a therapist might allow a greater source of strength in the face of the negative outcomes of therapy. These ideas will be explored again in the subsequent sub-theme.

In evaluating the work, participants can be seen to explore the question of difference. The main differences that participants identify appear to relate to the process of therapy, such as the pacing and planning of sessions, endings and boundary issues. A number of participants describe finding that the therapeutic goals are different when working with individuals with dementia. Rather than looking towards the future in the therapeutic work, participants describe working more in the here and now, or in the past thus facilitating their clients to retell their stories. Sophie emphasises this difference in her account considering how with a non-dementia client group she often works towards moving a client away from their past stories if she deems them to be obstructive to the therapy. In contrast, when working with an individual with dementia, she perceives being able to escape into this fictional place to be a more functional process and tends to allow her clients to reflect on their past more. Sophie explores her rationale for this difference in the following extract:

Sophie "*With someone with dementia, I guess you don't want to rock the boat too much because they are doing it for a reason, because the person and the future are terrifying and perhaps having that sort of escape and building a world around themselves where they can feel like they're slightly different and maybe in a slightly different kind of fantasy place isn't a bad thing*" [8, 350].

Sophie's use of the expression "rocking the boat" is interesting here and multiple interpretations can be considered in this extract. It could be interpreted on initial reading that she has identified a difference in terms of the fragility of the individual and the work. Sophie could be saying here that, for the clients, the self and the future in dementia are a terrifying experience in which retreating into a fantasy world is adaptive. She might also be allowing the client to retreat into this other world knowing that it is difficult to alleviate their difficulties. On a deeper level of interpretation, what Sophie could be expressing is an unconscious fear of destabilising something much more threatening to her own sense of self. Sophie stating "the person" is suggestive of her owning the fear that she is referring to here towards the person with dementia. This could be interpreted as a fear surrounding a threat to her identity as a therapist that the differences in working with individuals with dementia might bring. On yet another level, the fear experienced by Sophie could relate to a more personal threat to her whole future being in which the dementia work could draw attention to her own mortality. Her clients "building a world around themselves" can be viewed as not only being an escape for them but also an escape for Sophie from the threat that she might be experiencing. Whilst there is this invisible world surrounding her clients, she can perhaps feel distanced from them and therefore can protect herself from experiencing the existential threat. These ideas are explored further in the sub-theme 'The Detrimental Effect of Dementia on the Therapist and the Therapeutic Work'.

Although describing differences in their work with individuals with dementia, some participants perhaps experience the work similarly to their work with other client groups. It is apparent that participants work towards their clients needs utilising the same core psychological approaches. As a result of this, the label of dementia is on the whole disregarded. Furthermore, it is evident that participants perceive the effects of dementia on therapy to be quite minimal. The emotional functioning of clients is also perceived to remain intact thus facilitating the development of therapeutic processes, such as the therapeutic relationship, as with any other client. Participants can be observed trying to make sense of this tension between the differences and similarities of the work during the interviews. Mary, for example, reflects on difference in her account in regards to working with aspects of loss in therapy:

Mary "*Is it any different? I don't think, it's therapy. I don't think it's any different from doing therapy with.. anyone facing any loss, of any sort, really*" [4, 182].

This process of sense making during the interviews seems to lead to some confusion and contradiction for a number of the participants, including Mary. In the following extract Mary reflects upon the therapeutic relationship in her work firstly stating that there was no difference in the work but then stating that it was different:

Mary "*The process and the relationship for me is....it's no different really.. um.. I mean it is different but it isn't if that makes sense..*" [6, 288].

One interpretation of this contradiction could be that at a superficial level there are limited differences to the work but that underneath there are more subtle differences which Mary is finding difficult to verbalise here. For example, given the progressive nature of dementia and the different stages that an individual may be at, it could be that this variation in client presentation makes it difficult to identify the differences and similarities of the work thus creating ambiguity. Mary goes on to express how every individual is different regardless of a diagnosis. Another interpretation could therefore be that where she expresses difference in the relationship she may be referring to nuance and individuality that occurs in every person.

In contrast to the previous sub-theme in which it can be intimated that participants are holding on to a particular identity, in this sub-theme participants are perhaps searching for and attempting to define their identity as a therapist. They seem to do this through evaluating the value of their work and questioning whether the work is any different to working with clients' without a dementia diagnosis.

4.2.3 Therapist Motivations and Values

This sub-theme encapsulates participants' personal motivations and values concerning their therapeutic work. Throughout the accounts, participants express enthusiasm for their work, and highlight a number of aspects that inspire them to continue. These aspects will be explored in more detail below.

Participants use a variety of positive descriptors in their language to describe their experience of working psychotherapeutically with individuals with dementia including "*pleasure*" [Brenda: 2, 86] and "*interesting and creative*" [Julia: 2, 68]. Coming across as one of the most enthusiastic, Sian describes her work in a very positive light:

Sian "*There's something, I don't know what it is, it's just very.. satisfying, very rewarding um and it's not always like that, but it's almost like.. yeah it's exciting it's... interesting, it's very exciting I think, and it makes you want to go yay [shouts]*" [12, 569].

There is something quite palpable about this extract in terms of Sian's enthusiasm for her work. At a different point she speaks about educating others and it can be perceived from this quotation that she could be very inspiring for others. "Satisfying" and "rewarding" are also words that a number of participants use in their accounts. In particular, participants describe their feelings of satisfaction at doing a good piece of work and their feeling of reward at being able to make a difference to their clients. As Sian states above, however, "it's not always like that" and it seems particularly important from the accounts that participants experience the more positive aspects as well given the challenges of the work. It could be interpreted that these positive aspects act as a driving force enabling them to keep going in the face of difficulties. The difficult aspects of the work will be explored further in the super-ordinate theme 'The Detrimental Effect of Dementia on the Therapist and the Therapeutic Work'. For Sian, however, being able to make a difference through brief interactions with her clients appears to be her motivating factor:

Sian "*I think there's something about working with people with dementia that.. is, has both potential to be highly rewarding and can, I get, I always think like, you know, within five seconds you can make a difference.. sometimes and a big, big, big difference*" [8, 359].

In this extract, Sian perhaps struggles to articulate what motivates her altering her words several times until she gets her point across. Linking this to the extract above, in which Sian's enthusiasm is clear, this struggle of expression may be as a result of the immense excitement that she is feeling towards the work particularly where there are more immediate benefits for the client.

Being able to help clients through doing good work was also a motivating factor for Margaret as she describes in the extract below:

Margaret "*It's a feeling of actually being able to do a good piece of work where you can you know be a proper therapist and allow the emotions to be heard is quite satisfying*" [3, 134]

As was considered briefly in the previous sub-theme, Margaret appears to value being a "proper therapist". This extract suggests that, at least part of the time, she feels that this is not possible in the work. Reflecting across the accounts, the importance for participants in holding on to cases in which they have been able to be a "proper therapist" and where they perceive the therapy outcome to have been successful is very apparent. Julia, for example, describes holding on to the memory of successful cases in order to feel a sense of purpose in the work:

Julia "*I suppose, it's being able to hold in my mind the cases that I have felt have been quite successful that give me that sense of purpose*" [6, 259].

It can be interpreted that being able to hold on to these cases enables participants, such as Julia, to have a reason to continue the work and that these cases perhaps make the work more meaningful. In turn, this helps participants to carry on in the face of adversity working with this client group and reinforces the belief of future success. In Richard's account, he speaks at length in regards to a particular client case he values, a lady with whom he has worked over a number of years:

Richard "*I've always been, I've always felt really quite grateful to her because she's such a wonderful textbook example of how psychological therapies can work perfectly well for people who are really in relatively advanced, perhaps not late stages of Alzheimer's disease, but certainly moderate ones and have no conscious memory of having sat with us and talked about anything in particular other than that it was okay and they quite liked you, it was alright to talk some more with you.. so that I always thought that's been, and it's been hugely motivating*" [8,364].

Richard appears to describe how, prior to working with this particular client, he held some doubt as to the benefits of psychotherapeutic work with individuals with dementia. In working with this client intermittently, in parallel to his developing career, and in perceiving the work to be valuable, his beliefs about the work seem to change. Similarly to his experience of Tom Kitwood described in the previous sub-theme, he now seems to hold the case in high esteem as a success story which provides him with the motivation to continue the work. Reflecting on this further, it could be interpreted that what these cases provide for participants is an increased sense of self identity as a therapist in an otherwise uncertain and perhaps disempowering position. As with the previous two sub-themes, the concept of identity becomes evident here.

Participants also express appreciation for the variety in the work. Many of the participants work in an older adult setting which provides them with a range of presentations in the older adult population aside from dementia. Additionally, a great deal of variety is apparent within the work with individuals diagnosed with dementia in terms of the type of work that therapists might carry out and from which, it could be inferred by participants' accounts, they derive satisfaction from:

Julia "*I think I enjoyed it because it's got such a mixture of some really good opportunity for psychological therapy, you can really use a range of different* *therapies but also there's quite a strong neuropsychological element to the job and I particularly liked that work as well*" [2, 60].

A number of participants also speak about the value that they hold for the work and how honoured and humbled they feel in working psychotherapeutically with individuals with dementia. Julia, for example, reflecting on her experience of working with a client who died during the course of the psychotherapeutic work, recounts how privileged she feels in being able to hear her client's life story in great depth:

Julia "*..the one area I have worked with people where clients have actually died during the course of therapy and I think I was really struck, once that happened, of how important that therapy had been, that I felt in such a privileged position that I was the last person to hear their life story and their life story, in a lot of detail as well*" [5, 229].

This is a poignant moment in Julia's account in which it could be argued that the death of her client enlightens her to the importance of her psychotherapeutic work and her role as a therapist. Similarly to Sophie's experience highlighted above, there is a temporal feel to Julia's experience here. In contrast to Sophie's experience, however, in which the dementia work was perhaps experienced as an existential threat to the self, Julia's experience of death could be perceived as being more positive. It could be interpreted from this extract that Julia's experience is one of decorum and honour in which her sense of self as a therapist has been bolstered by this experience. Reflecting on being the last to hear the client's story also carries with it a validation and reinforcement of that client's existence as a whole person with a life and history despite their changed condition as a result of the dementia.

Finally, it could be claimed from the accounts that participants are motivated by the work of key figures and psychological models within the dementia field. These figures such as Carl Rogers, Tom Kitwood and Linda Clare influence participants' therapeutic practice and also may provide participants with a reason for continuing with the work. It can be observed from Sian's account, for example, that she is heavily influenced by the person-centred approach in dementia care:

Sian "*I was lucky to be exposed to a person who was a dementia care mapping trainer and so I know quite a lot around person the sort of person-centred the model of dementia and that has been the most influential thing ever in my whole entire life [laughs] basically and, sort of, is my main motivating, sort of, factor there really*" [4, 160].

For Sian, the person-centred model is a significant motivating factor for her in continuing her work. It is apparent from her narrative that she embraces the model whole heartedly and with tremendous enthusiasm. This concurs with her overwhelming excitement and passion for the work explored above. Perhaps in order to emphasise how much the model has influenced her practice, Sian describes the model as being the most influential aspect of her entire life. A deeper interpretation could be that Sian has in fact embraced this approach as part of her self identity as a therapist or even her whole self and therefore it feels as if it is a part of her entirety. Reflecting on the theme of identity further, as suggested in the earlier sub-themes, it could be that these models or key figures provide participants with an increased sense of identity, as a therapist working with individuals with dementia, which they otherwise did not have.

4.3 Bridging between Two Worlds

Bridging between two worlds encapsulates participants' experience of making sense of their clients' experience of dementia and understanding the emotional and psychological needs of their clients. In gaining this understanding of their clients' experience, participants seem to be connecting their own world with that of their clients, and acting as interpreters between these two worlds. The relationship between participants and their clients appears to be significant in linking these two worlds, and the ability to view their clients as individuals is conceived to be important. The following sub-themes: Understanding the Client's World; Supporting the Client's Emotional and Psychological World and Making a Connection with the Individual, explore these ideas in more detail.

4.3.1 Understanding the Client's World

Understanding the client's world explores participants' experience of understanding their client's experience of dementia. It could be argued that, in attempting to understand their client's experience in the narratives, participants endeavour to put themselves in the client's position and try to imagine what it must be like to have dementia. Sophie, for example, highlights how through working with her clients she can begin to understand their experience. She emphasises that whilst she can imagine, she can never actually know exactly what they experience:

Sophie "*It's a kind of learning process as well because you're hearing about a world that you don't know about.. you can imagine what it might be like to have dementia but obviously you don't know*" [9, 429].

A number of participants, as Sophie does in this extract, adopt the word "world" in their narratives to describe their clients' experiences. This is interesting, and it could be interpreted that this implies that their clients are in an altogether different place to the participants. As a result of this it could be inferred that participants have to work hard in order to connect with and understand their clients in this separate world. Similarly to Sophie above, Brenda emphasises how she is required to use more of her imagination in order to understand her clients' experience:

Brenda "*So I have to sort of I have to use much more of my imagination.. to try and find out, what's it like for that person?..*" [3, 136].

Again reflecting on the concept of different worlds Brenda's need to use more of her imagination would imply that there is a large space in between herself and her clients, perhaps more so than when working with other client groups. It could be suggested that, in order to understand her clients' experience fully, she would need to bridge this gap and tries to do so through the use of her imagination. Brenda's use of a question in this extract might imply that she has not yet been able to fully understand her clients despite using her imagination as much as she can. She might also be questioning in herself whether it is at all possible to traverse this gap. Given her flexible approach to the work, using her imagination could be considered a further strategy she employs in the face of the challenges in that work.

Participants also appear to try to make sense of their clients' experience through drawing comparisons with other conditions such as other progressive illnesses or physical health issues. Brenda, for example, reflecting on the progressive nature of dementia and her clients' experience of this, draws comparison between dementia and conditions such as diabetes, seemingly in a further strategic attempt to understand what her clients might be experiencing and to create a mutual understanding between them both:

Brenda "*So we very often used.. parallels like multiple sclerosis, cancer, that kind of stuff diabetes, yeah diabetes is a very good model because it can't be cured, it can be treated*" [6, 259].

The extract shows how she is perhaps looking for a particular model to assist her in her understanding of her clients' experience of dementia. This would suggest that it is difficult for Brenda to access the world of her clients and she, therefore, needs to draw on something more concrete to enable her to enter their world and develop an understanding of their experience. What is also interesting here is Brenda's use of plural suggesting that she is in fact creating a shared understanding with her client. It could therefore be interpreted that by employing these models it is possible to bring the two worlds closer together.

In the majority of accounts, participants recount past examples of their client work and stories from their clients. These examples can be considered to be a useful way of helping participants to illustrate their psychotherapeutic work, or particular aspects of their own experience, and also enable participants to explore their clients' experience and to communicate their understanding of this experience to others. Having described her work with one client, Sophie reflects on her clients' stories and how they might be experienced by her clients:

Sophie "*I think for some people actually the idea that they might be contributing to your knowledge and helping you into people's minds I think would be a good thing for them, they would like that*" [9, 439].

Sophie seems to perceive her clients' stories as a way of understanding their experience and being able to reach into their world. It could be argued that this is reflected in her conjecturing that this would be positive for her clients in feeling that they were contributing to others' knowledge of the dementia experience. "Helping you into people's minds" might imply that Sophie experiences individuals with dementia as having very different internal worlds to herself and those without dementia and there is thus a need to join the individual in their mind in order to understand their experience. This supports the notion of separate worlds that need to somehow be traversed by participants to understand their clients' experience as suggested earlier. Sophie expresses some regret in not being able to capture her clients' experience more explicitly through recording sessions or keeping a written record. It could be interpreted that this would enable Sophie to permanently maintain a connection between the two worlds, adopting the role of translator between them. This is a position that other participants appear to assume. Sian, for example, emphasises the difficulty for individuals, such as care staff, in being able to understand their clients, perceiving that this can lead to a lack of empathy towards them:

Sian "*Often people are tearing their hair out because they don't they can't understand and we when we don't understand then people's empathy just goes out the window so I think for me um.. just anything that helps increase empathy of anybody and understanding I think is a real key*" [12, 562].

In her account she consequently can be observed to take on the role of interpreter in response to this difficulty, helping others to make sense of the dementia experience in order to facilitate empathy, and bring the two worlds closer together.

It could be argued from the accounts that participants find it beneficial to develop an understanding of particular aspects of their clients' persona, such as the location of cognitive impairment or personality characteristics prior to the dementia, in order to be able to fully understand their clients' experience. For Rebecca, it appeared to be important to reflect on her clients' disposition and their ability to manage difficulties in order to inform her understanding of their experience of dementia:

Rebecca "*..trying to find something a bit about perhaps their temperament as well as, you know, any significant events.. I suppose, yeah, things like temperament you know might, and how they've reacted to difficulties in their life, might sort of give a clue to what the experience of dementia might be*" [4, 181].

Rebecca's expression "give a clue" here conveys the idea that the task of understanding clients with dementia is a complex one in which there needs to be a significant amount of explorative work. As highlighted in an earlier extract, Rebecca values formulation in her work and it could be perceived that this enables her to explore in a more structured way. This extract conjures up an image of the person with dementia being lost in some way. Developing this interpretation further, it could be that Rebecca uses the clues, such as temperament or previous coping abilities, in order to find her clients and develop her understanding of their present experience. Sian articulates a similar experience of endeavouring to understand her clients by acting as "a detective":

Sian "*I think for me it's about making sense, I think that's the thing about working with people with.. all sorts of different cognitive problems, but I think particularly with people with dementia is about just trying to make sense. I think that's for me quite rewarding if I've worked out like been a bit of a detective [laughs]*" [12, 551].

For Sian, being a detective and being able to make sense of her clients experience is perceived as rewarding. The descriptions of these experiences are suggestive of a difficulty in accessing clients' experiences in a straight-forward manner and again conjure up the idea of there being a separate world that the dementia creates. In order to access and make sense of this world both Sian and Rebecca need to take on the role of a detective. Whilst they both take on this role, it could be considered from their quotations that Rebecca takes this role more seriously than Sian evident in their differing use of language and tone. This corresponds with earlier extracts from both these participants highlighting variation in their experiences.

Participants also can be seen to utilise particular turns of phrase to facilitate the psychotherapeutic work with their clients and to generate an understanding of their clients experience of dementia. Brenda, for example, highlights her struggle to understand her client's experience by employing the idea of "holes in the mind" that was suggested by the client:

Brenda "*She actually did say 'I've got holes in my mind.. it's still there but I've got holes in it' [] And once she was in a hole you couldn't follow her because I don't have holes in my mind*" [10, 452].

This expression potentially provides a valuable way of understanding what her client might be experiencing. Brenda emphasises in this extract the difficulty in being able to connect fully with her client when her client was in a "hole" as she was not able to join her having not experienced dementia herself. Following previous interpretations in this sub-theme, yet again there is a sense of another world in which individuals with dementia reside which is difficult for participants to access and identify with. Again it could be conceived that Brenda employs a strategy in order to overcome the difficult aspects of the work. Reflecting on the theme of identity it could be inferred that in this sub-theme participants in trying to understand their clients' world, are in fact attempting to identify with the individual and their sense of self.

4.3.2 Supporting the Client's Emotional and Psychological World

This sub-theme explores participants' perceptions of their clients' emotional and psychological needs and their role in supporting their clients with these needs through therapy. It could be argued from the accounts that what is particularly significant for participants is assisting their clients in coming to terms with and managing the losses associated with the dementia diagnosis. Mary, for example, identifies loss as the central aspect of her psychotherapeutic work with clients with dementia:

Mary "*The work very much very often centres around loss and denial.. acceptance, grieving.. and coming to terms with.. with the losses whilst being very aware of them..*" [4, 179].

What also appears important for participants is being able to support their clients in making adjustments to the condition as it progresses. Richard highlights the need to support individuals and assist them in managing their lives in preparation for deterioration that might occur:

Richard "*People need quite a lot of support in order to come to terms with the diagnosis and overcoming the perceptions of stigma and being actually able to then.. you know, be much more out there in the way they can organise and prepare their lives for.. a possible quite lengthy period of deteriorating functioning and health*" [11, 504].

It could be interpreted that the existential theme is again apparent in these extracts. What both participants could be touching upon here is the process of loss and adjustment that their clients might be experiencing following an existential crisis, in which they have received a dementia diagnosis. Thus they perhaps perceive their roles to be supporting clients through this process helping them to re-organise their lives to adjust to the diagnosis and prepare for the future. Linking in to Julia and Sophie's existential experiences in the earlier super-ordinate theme 'Considering the Psychotherapeutic Work', one could speculate that this work might impact upon Mary and Richard's own sense of self forcing them to face up to their own existential beliefs.

Common to participants' accounts is the need to provide a containing and validating space in which their clients can feel listened to and their distress can subsequently be alleviated. This can be illustrated by Sian who conveys hope of creating a validating environment in her work. She identifies psychological therapists as being in a particularly strong position to be able to do this:

Sian "*..psychological therapists and counsellors.. because of their training feel more able to be with someone in their distress and join them in their distress and hear them and listen to them without trying to.. jolly them along or make them feel better or make them feel happy and that actually the process of trying to jolly someone along and make them feel happy can make someone quite.. upset and unheard and not validated and angry*" [9, 430].

Sian expresses here being able to meet her clients on an emotional level where perhaps other individuals with less training or awareness might not be able to do so. Her use of the word "join" in this extract again, as with the earlier sub-theme 'Understanding the Client's World', conjures up an image of different worlds. It could be interpreted here that therapists and counsellors, because of their training, have been equipped to enter into the world of their clients and as such are able to validate their emotions. However, for others without this training, attempting to help the individual can in fact push these different worlds further apart creating further distress for the individual. This is an interesting contrast from other participants views, highlighting the ambiguity evident across accounts explored in the previous super-ordinate theme.

It could be inferred from the majority of accounts that participants wish to support their clients' emotional and psychological world. For a number of participants, accessing the world of their clients is made more complicated by the confusion of both participant and client experiencing different time periods, such as past and present reality. Julia, for example, reflects on the need to be sensitive with clients to ensure that she joins them in whatever they consider to be their present world:

Julia "*You need to be quite sensitive to how you even talk about that and make sure you're discussing it in a way that makes sense to the person, so for them it's their present, you're using present tense and not past tense*" [8, 389].

By paying attention to her choice of language, Julia is able to meet her clients in their own world. It could also be interpreted that in meeting the client in their own world Julia is acting as a bridge joining her client's world whilst still trying to hold onto her own sense of reality. The idea of different time periods is also apparent in Kerry's account in which she highlights the need for clients to be living in their past rather than in the present:

Kerry "*They admit, and I can see pretty easily, that they're on much thinner ground when they're talking about the past and this helps their confidence to increase and they can acknowledge that they can say that when we go back.. I sort of know where I am, you know. When we talk about what's happened recently, I feel very lost*" [2, 66].

Kerry makes an interesting slip here when she uses the term "thinner" rather than "thicker" ground. One interpretation of this could be that it is Kerry in fact that is on much thinner ground when her clients are talking about the past, particularly if the client considers their past to be their present. Joining her clients in their world where the past is the present could create a significant challenge for Kerry, potentially leaving her feeling lost and isolated. Taking this interpretation further, it could be suggested that perhaps Kerry and other participants, in joining the world of their clients, leave behind aspects of their own world. What they might be leaving behind is a sense of what is real to them, a reality which could be perceived to shape their own self identity, without which they might feel lost. In the previous super-ordinate theme 'Considering the Psychotherapeutic Work', it was suggested that participants are searching for their identity and are able to develop a sense of self as a therapist through the motivating aspects of the work. In contrast, it could be claimed here that participant identity is lost in the process of connecting with the client in their differing world.

4.3.3 Making a Connection with the Individual

This sub-theme explores the relational and emotional connection between the participants and their clients. Even prior to enquiring about participants experiences of the therapeutic relationship when working with individuals with dementia in the interviews, the majority of participants emphasised the importance of the therapeutic relationship in their work. Kerry, for example, highlights her experience of how powerful that relationship has been in her work with clients:

Kerry "*I kind of.. without meaning to, sort of covered it then, you know, the therapeutic relationship is the most important thing, you know, as research shows us that, you know, the most important factor is the bond or the relationship regardless of who the therapist is [], the sort of constellation of symptoms that the patient presents with blah blah blah and, you know, the most important thing is the relationship I.. definitely.. believe that so I think, I think it's... something that can be a very, very powerfully positive part.. of therapy*" [5, 222].

Kerry emphasises that regardless of a diagnosis, such as dementia, or who the therapist might be, the relationship still remains central to the therapeutic process. It could be seen in this extract from Kerry's language that she feels strongly about the role of the therapeutic relationship in the work and is perhaps anxious to get this point across in her narrative. This is evident in her repetitive use of the words "you know" and "very" in the extract. Sian also outlines in her account the centrality of the therapeutic relationship:

Sian "*I spend quite a lot of time helping a person to feel safe and to feel comfortable and to feel that therapeutic relationship with somebody so that they don't have those, sort of, maybe, psychological barriers that might come in when we start talking about memory problems*" [7, 307].

Sian perceives the therapeutic relationship as a valuable way of breaking down "psychological barriers" in her work. Reflecting on the idea of "barriers" further, and drawing again on the notion of different worlds, it could be interpreted that Sian and her clients are experiencing different worlds which are separated by these metaphoric barriers. Thus the therapeutic relationship is experienced as a useful tool by Sian to break down the barriers and connect with the client's world.

It could be surmised from the accounts that what is significant to the majority of participants is being able to connect with the individual as a whole person rather than focusing on the dementia label. Additionally, participants recognise that each client's experience is very different from the next person, despite sharing the same or similar diagnosis. Brenda, for example, outlines the importance of seeing the person before the dementia in the following extract:

Brenda "*Most importantly is to look at people's humanity, to see the person first and the dementia second, like you would do with a person with a broken leg, like you would do with a person with an amputated leg, or a person with a brain tumour*" [18, 860].

Through the use of comparison with other health conditions, Brenda emphasises here the stigma that is attached to having a diagnosis of dementia, and the difficulty in seeing the individual and not the label. As has been considered in earlier sub-themes, Brenda perhaps finds it difficult to understand her clients' experiences and using comparisons with other conditions enables her to connect with her clients in their world more easily. It could also be, that for Brenda, focusing on the relationship and the human aspects of her clients acts as a protective strategy thus defending her from the more difficult features of dementia. It could be considered that this protection actually preserves her sense of identity as a therapist which is impacted upon by the difficult aspects of dementia.

Participants, such as Richard, also emphasise that the specific diagnosis of dementia, such as Alzheimer's disease or Vascular dementia, is somewhat irrelevant as their experience of each individual is different despite the diagnosis:

Richard "*..actually it doesn't matter whether we talk about Alzheimer's disease in particular or whether we talk about dementia, the dementias in general, because no one Alzheimer's disease is exactly like the next*" [9, 437].

For these participants this might suggest that the connection is made with the individual whilst the diagnosis is secondary to this. By focusing on developing a relationship with the individual client, and not centring on the label of dementia, perhaps enables participants to bridge the gap between the different worlds during their work. Thus it could be conceived that focusing on the relationship in the work facilitates the connection between the two worlds. In turn this connection perhaps enables participants to maintain their identity as 'successful' therapists.

It could be argued that what is common to participants' accounts is that the most significant aspect of their relationships with their clients is the emotional bond between them. Interestingly, many of the participants highlight the fact that their clients frequently find it difficult to remember the therapeutic relationship in terms of the content, such as the name of their therapist, but always seem to remember the relationship on an emotional level. Consequently, participants report that they predominantly connect with and engage their clients on an emotional level and pay less attention to the content of the therapy. This is encapsulated below where Richard emphasises that, despite memory problems, his clients are able to remember the relationship with him and particularly whether this relationship was a positive or negative one:

Richard "*Even though people might not remember who I am, or what we talked about, people can always remember whether they liked me or not*" [6, 267].

Julia also stresses the importance of the emotional content of therapy as a way of connecting with her clients despite them not always remembering the relationship:

Julia "*So often people will forget my name, and they'll forget where they were going to meet me and what the appointment time and date are, but they'll remember what we talk about at sort of an emotional level*" [5, 206].

Sian emphasises that the factual content of therapy is less important to her whilst it is valuable to pay attention to the emotional aspects as a way of understanding her clients and enabling them to communicate with her:

Sian "*I don't actually feel that.. in sort of therapeutic work with people it's so much about what's factually being said, it's about.. I see it as looking for.. you know, what is this, what must this person be feeling if they are saying such and such, I think what's that communicate to me about how they're feeling*" [11, 501].

What seems to be common in the accounts, therefore, and is demonstrated clearly in the above quotations, is that emotions are valuable in facilitating the therapeutic relationship. It provides a way in which participants can communicate with and understand their clients despite their memory impairments. As a result, emotions appear to function like a shared language between participants and their clients, facilitating them in making a connection between their differing worlds. In making this connection, as described above, participants are possibly able to maintain their sense of identity as therapists as they might with other client groups.

4.4 The Detrimental Effect of Dementia on the Therapist and the Therapeutic Work

This super-ordinate theme aims to capture the more difficult aspects of the psychotherapeutic work with individuals with dementia as perceived by the participants. Throughout their accounts, there is evidence that participants emphasise the complexity of dementia and the challenges and uncertainty they face in their work. What is particularly interesting about this super-ordinate theme is participants' use of language and metaphor in describing these experiences. These aspects will be explored further in the following sub-themes.

4.4.1 Personal Impact

Throughout the accounts, participants allude to the impact of the dementia work on them at a personal level. Whilst there are positive motivating factors for carrying out the work, it can be seen to impact negatively upon the participants.

A number of participants highlight the distressing nature of working with individuals with dementia. For example, although Sophie emphasises the positive aspects of the work, she states that she only feels able to do the work as a minority part of her role:

Sophie "*I do like working with people with dementia, it's very interesting and challenging, but I couldn't do it as my entire job, it has to be a kind of a smallish part of the job*" [1, 44].

It can be interpreted that for Sophie working with people with dementia feels very intense and she must, therefore, limit this work in order not to feel overwhelmed by it. This can be understood in the context of an earlier extract from Sophie in which it was perceived that she was experiencing a threat to her sense of self from the work. Thus working entirely with this population is likely to enhance this threat and reduce Sophie's sense of identity as a therapist. Brenda also describes the difficulty of the work and the potential for it to impact upon her personally:

Brenda "*I think if I wasn't really made out of plate iron, I think I would have moved out of..*" [13, 636].

Using the description of "plate iron", it could be interpreted that Brenda is accentuating the need to be strong in order to carry out the work, suggesting that otherwise she would not cope with it. It could be considered that Brenda draws strength from the different strategies she employs which have been highlighted in preceding sub-themes. On deeper interpretation, plate iron was a material used to make armour, thus what Brenda might also be saying here is that there is a need to protect herself personally from the impact of the dementia and the work. Without this personal protection she would not be able to continue. It could be interpreted here that Brenda experiences dementia as something threatening. This is something that is evident throughout her account in her use of language and can also be seen in some of the other participants' accounts. Kerry, for example, in describing the importance of having adequate neuropsychological assessment when working with clients, spoke about being "*armed with that knowledge*" [4, 156]. Again this is suggestive of the need to be equipped with some form of protection, in this case having the weapon of knowledge against a perceived threat. Taking this further, given the difficult nature of the work, it could be suggested that this threat is to participants' sense of self identity as a therapist. Thus the need to arm yourself against this threat to self is important in order to maintain your identity. This is reminiscent of the earlier super-ordinate theme 'Considering the Psychotherapeutic Work' in which participants attempt to maintain their identity through the motivating aspects of the work.

Also evident in a number of participants' accounts are the personal sacrifices that they seem to make for their clients and the psychotherapeutic work. This can be seen in terms of the extent to which they are willing to adapt their practice for their client and the roles they may take on in their work. The most extreme example of personal sacrifice can be observed in Brenda's account in which she describes working hard to maintain the same appearance to ensure that her clients in the more advanced stages of dementia are able to recognise her:

Brenda "*In terms of the actual cognitive damage that the dementia is doing it starts to bite really home for my own.., in terms of impact on my own personal life.. because.. you have to make sure that the client somehow knows that you're the same person [] you can't actually do too much about your hairstyle.., you can't change it too often, if you do have it cut don't cut it too drastically because they might not recognise you. If you have different glasses keep your old ones so that they can remember you. With one lady I even had to make sure that each time I visited her I was wearing the same clothes... which is a big thing because I had to put it in my diary saying wear those clothes..*" [4, 170].

Brenda appears to be working flexibly and makes tremendous personal sacrifice for her clients. However, as a consequence of these strategies, her account implies the work has a detrimental effect upon her. Brenda's choice of language is interesting here in terms of the idea of "biting home" again suggesting that she is under personal threat from her clients' dementia. Reflecting on the idea of identity considered above, it could be interpreted that the threat is to Brenda's sense of self, in that she does not feel able to change her appearance and has to maintain strict boundaries which may prevent her from remaining true to her own identity. Unable to maintain her sense of self and thus left unprotected, it could be construed that Brenda might struggle more with the challenges of the work. Linking back to the earlier super-ordinate theme 'Bridging between Two Worlds', Brenda gives the impression that she is trying to connect with her clients by means of various strategies. It could therefore be perceived that in this extract Brenda is again attempting to traverse the two worlds this time by maintaining the same appearance to stay connected with her clients. To a lesser extent, it could be argued that Sian also makes personal sacrifices for her clients, ensuring that she adheres to a person-centred model unreservedly:

Sian "*I kind of see it as every single intervention, every single conversation or action, or anything at all that I do [laughs] with someone with dementia that I've got in my head that model in my mind. So whether I'm just walking from the nursing base to the doctors' base where I might be reading some notes, I always give myself [laughs] at least ten minutes to make that journey because I might encounter someone with dementia on the way who might be.. in distress or might speak to me and I would feel that it would be very non person centred to ignore that person or to rush by..*" [5, 206].

In contrast to Brenda, Sian appears to be more at ease with the personal sacrifices she has to make, as implied by her laughter as she speaks. Reflecting on this difference, it is clear from Sian's account that she identifies with the person-centred model whole heartedly, and as described earlier, it could be considered to form part of her identity. Perhaps as a result of having a clearer sense of identity, it could be speculated that Sian feels more grounded within herself than Brenda, and is therefore more able to manage the threats to self that these personal sacrifices engender.

Participants also reflect in their narratives on the different roles they are placed in by their clients, both in relational terms through a process of transference, or due to client confusion. Common roles emerging from the accounts are becoming the daughter or son and granddaughter or grandson. It could be that these roles create difficulty for participants as Julia describes in the following extract:

Julia "*People can also become quite confused about who you are, and I've had people shift in the therapy to thinking I'm their daughter or their sister sometimes, and that's quite challenging on how to know how to deal with that*" [8, 392].

Sophie also describes her work with one male client in which her role changes from therapist to a young female fantasy figure:

Sophie "*..see me in a different light as this kind of young woman that he could sort of escape into this sort of fantasy world really where he could like tell me all these stories from his youth... he wasn't really talking about the present time at all anymore and the reality, you know, that he was an elderly man with dementia and I was his therapist, it was more you know this kind of flirtatious story teller person*" [7, 312]. .

It could be interpreted that Sophie feels uncomfortable in managing this situation with the change of role. This is evident in her use of the word "flirtatious" which can be considered to be an inappropriate way to behave in a therapeutic encounter. This extract also brings to light the notion of different worlds explored in the super-ordinate theme 'Bridging between Two Worlds'. It could be inferred from this extract that Sophie is unwittingly being pulled into this "fantasy world" of her client away from her present reality in which she strives to maintain professional boundaries. Again this could be linked to the concept of identity loss in which Sophie's sense of self as a therapist is under threat from this imposed role change.

For a few participants, taking on different roles also means becoming a member of the opposite sex. Brenda, for example, describes in her account working with a male client who because of her short hair and white shirt believes that she is a male vicar:

Brenda "*..anything with long hair was a woman to this man, anything with short hair was a man, so he went into man to man talk with me which was quite embarrassing.. because sometimes he could be very explicit [laughs] and I learnt a lot about what men are up to when they're just men together[], quite exciting because you can cross the gender gap...where otherwise you wouldn't have that option.. while at the same time.. I want to stay as my own gender, thank you [laughs], and so it's.. it's quite a challenge managing those assaults, unmeant assaults, on your own privacy and on* *your own feelings*" [5, 210].

Here Brenda describes both the positive and negative impact that being assigned to this male role brings. On the positive side, it enables Brenda to connect with her client understanding what it is like to be male and perhaps linking more closely with her client's world. However, this experience is evidently a challenging one as she again draws on a threatening form of language in her choice of the word "assaults" to describe the experience. It could be interpreted that what Brenda is implying here is that her feelings and privacy have been attacked albeit "unmeant". The way that Brenda laughs after she expresses her wish to remain with her own gender suggests that this is something that is very personal to her. Analysing this further, it could be that what is actually under threat of attack is her sense of identity as a woman.

It could be argued from the participants' accounts that the psychotherapeutic work impacts upon participants' own personal existential beliefs. In particular, the work forces them to confront their own issues of aging and mortality, and reflect on how they might cope with a diagnosis of dementia. Reflecting on client loss again, Julia acknowledges that the experience has provided her with a sense of perspective about her own life, and has awakened her to consider her own mortality:

Julia "*I suppose I took away from me a sense of actually the little worries in life really don't matter and, you know, there's really no point focusing on things like that, and so I felt, I suppose I felt like I learnt something at quite a personal level really, sort of makes you realise your own mortality as well*" [6, 268].

Similarly to Julia's experience of mortality explored in the super-ordinate theme 'Considering the Psychotherapeutic Work', this is another poignant moment in her narrative. It could be interpreted that the death of her client prompts her to question and re-evaluate her own existence. Again this appears to be a positive experience for Julia, and there is a felt sense of calmness about the way she describes this experience. Having gained this fresh perspective, it could be perceived that she has already begun to incorporate this new way of being in her life.

4.4.2 Swimming against the Tide

"*Swimming against the tide*" [9, 409] is an expression used by Sophie to describe her client work and the difficulty of doing therapy with individuals with dementia in comparison with other individuals. In this sub-theme, 'swimming against the tide' has been used to describe participants' awareness that dementia is a progressive disease and as such the work is complex, challenging and often very frustrating.

Recognising the progressive nature of dementia, a number of participants highlight the importance in their work of setting realistic goals, re-assessing and adjusting goals and being prepared for goals to change frequently. Kerry, for example, considers how therapists need to be responsive to the rapidly changing nature of dementia and her experience of continually adjusting expectations and goals and remaining open to anything that might occur:

Kerry "*The therapist always has to be sensitive to the fact that this is a changing.. condition so what they might have thought was possible even a month or six weeks or two months ago may not be possible anymore.. so there is a sense of constantly sort of adjusting, perhaps expectations or perhaps goals, or just being open to what is.. what is brought um.. and just being open to what can be achieved..*" [7, 310].

At the beginning of this extract, Kerry appears to be describing the difficulties that she faces in her work given the progressive nature of dementia. In doing so the image of 'swimming against the tide' is conjured up highlighting the struggle that the progressive nature of dementia generates. During the second part of the extract it could be viewed that what is important for Kerry is acceptance of the progressive nature of the disease, adjustment and holding a pragmatic position. On further analysis, this latter part engenders a feeling of continuous movement both for Kerry and her clients as they adjust to the progression of the condition. Rather than 'swimming against the tide' it could be interpreted here that Kerry is 'going with the flow' remaining flexible and open to what her clients might bring.

Participants also describe working with clients who have reached the end of their illness and have died. These experiences can be seen to be stark and distressing reminders for participants of the progressive nature of dementia bringing awareness to the fact that there is often no happy ending to the work:

Brenda "*There was an end to it, the end was death.. and that is quite harrowing*" [9, 428].

As well as highlighting the ultimate progression of dementia and the distress that this causes, this extract also perhaps accentuates the relentlessness of the work for Brenda. There is a felt sense here that the only way in which the work can end is through something as permanent as death, which is understandably quite disturbing for her. This experience again brings to light the existential theme evident across participants' accounts potentially alerting Brenda to her own mortality.

In Mary's account she reflects on her experience of working with individuals in different stages of the dementia process. Working with individuals in the later stages prompts her to consider what her clients in earlier stages are progressing towards:

Mary "*I guess the fact that it's progressive and you know that from the beginning, and that I work with people say from the mild cognitive impairment right through to advanced.., even if it's not the same person that I'm seeing across that journey.., being exposed to it I think definitely doesn't make it easier, it makes it harder.. but makes it, because it's on the cards its yeah having that awareness rather than denial about it I think.. helps a bit...*" [9, 414].

Although facing this progression could be difficult for Mary, she reflects on the value of having an awareness of what the outcome for her clients will be, rather than being in denial about it. Mary's choice of language is interesting here. Describing "being exposed" to something that is "on the cards" conjures up an image of being devoid of protection from harm that is known to be coming but has not yet arrived. As Mary explains this is a difficult position to negotiate but being alert appears to provide some form of protection for her. This difficulty is evident in her speech in which she conceivably grapples to get her point across. It could also be that she is recognising here the significance of being emotionally prepared for what is to come.

Reflecting on the difficulties that the progressive nature of dementia might present for participants, a link could be made with the construct of identity evident across all super-ordinate themes. One interpretation could be that the progressive nature of dementia in therapy is considered a threat to participants' identity as a 'successful' therapist as it prevents them from ever achieving the positive outcomes they might when working with individuals without dementia. Thus participants try to set achievable goals and perhaps lower their expectations in therapy in order to protect themselves from this exposure. In support of this idea, it is evident in the accounts that participants experience pressures from external sources which perhaps exacerbate the need to be 'successful' and show positive outcomes in therapy, consequently increasing the threat to their identity. In particular, participants such as Mary [7, 316] or Sophie [10, 475], emphasise the external pressure to provide an evidence-base for their work whilst Rebecca [3, 134] emphasises the pressure to work both quickly and effectively. Furthermore, some participants, such as Richard [10, 475], appear to experience threat at a policy level in terms of the inclusion of dementia in service development. An alternative interpretation for the difficulties faced by participants as a result of the progressive nature of dementia, reflecting on the existential theme evident elsewhere, might be that what participants are exposed to when facing the progressive nature of dementia and the ultimate ending of death is their own mortality which they are reminded is also "on the cards".

A further challenging aspect relating to the progressive nature of dementia perceived to arise from participants' accounts is the concept of stigma. A lack of understanding from other people surrounding therapy with individuals with dementia could be viewed in the accounts. The main misconception about providing therapy for individuals with dementia is considered to be that their cognitive deficits, particularly memory, would be too impaired to be able to benefit from it. Consequently, therapy is perhaps thought of as a last resort when all else has failed. Sian describes an experience her colleague had with an unnamed outside organisation that was unable to see the benefit of the psychotherapeutic work:

Sian "*The members of this organisation just couldn't see how it could possibly be relevant to people with dementia because they wouldn't be able to understand because their brains are too, what did they say? Their brains are too... I don't know, something* *very derogatory anyway...Frazzled or tangled up or, I don't know, their brains are just not capable of doing counselling*" [16, 756].

The image of the individual with dementia as a frail elderly person with a "frazzled" and "tangled" brain, unable to benefit therapeutically, seems to create a great deal of frustration for Sian. It is evidently important to her, as with other participants, to dispel these myths where possible. This misconception can also be considered at a societal level, for example in the images that are portrayed in the media, or in the language that is used to describe individuals with dementia. In the following extract, Mary describes her experience of how society has responded to dementia:

Mary "*I find it a really painful illness.. but I think that personally is more due to the system around it that.. society.. thinks it's.. society tries to deny it happens society doesn't really care about it and even though there's all this pushing out with dementia strategy we find at a grass roots level.. its still very much a hidden illness and people when you say the word dementia people automatically think of someone in the early stages in a nursing home.. incontinent unable to eat..*" [2, 95].

For Mary, society's response to dementia and inability to recognise the needs of individuals is perhaps more distressing for her than the work itself. Coming up against stigma in the work can be interpreted to be a very personal experience for participants. Reflecting on the concept of identity again it could be that the stigma surrounding the work is quite destructive to participants' sense of self as therapists. Perhaps in response to the lack of understanding and stigma surrounding dementia and psychotherapeutic work with the dementia population and the associated identity loss, participants stress the importance of raising awareness, educating others and generating research surrounding their work. A number of participants highlight the need to promote their work with their clients. Julia illustrates the importance of emphasising that a dementia diagnosis does not make therapeutic work impossible. As with some of the other participants, she also wishes to publicise the role that psychology can play in the diagnostic process within memory clinics:

Julia "*I think, you know, one side is really just promoting psychological therapies generally as a treatment of mental health disorders and stressing that a diagnosis of* *any dementia shouldn't be a kind of contra-indication but then the other side, and one that I'm kind of quite involved with now, is really promoting the need for more of a psychologically driven memory service*" [10, 452].

One interpretation of this move to promote psychology within memory services could be that in doing so Julia, and other participants, are able to be influential right from the beginning of the dementia process. Thus in promoting their work at this level they may experience less stigma and they can establish a firm identity in the work.

Another way in which participants possibly promote their work and understanding of dementia is through sharing ideas with other professionals and educating colleagues. Indirect work, such as increasing understanding of dementia with care staff, could be regarded as a significant part of their role and facilitates a wider approach to the care of individuals with dementia. Given Sian's enthusiasm in adopting a person-centred approach, she is understandably particularly keen for all staff working with individuals with dementia to employ this method in their work. She identifies the lack of knowledge associated with dementia to explain why staff might not be working in a person-centred way and deems it to be her job to educate and increase their understanding:

Sian "*You know this person is responding in this way to this person because they don't actually realise they don't actually understand and if they did understand, and that's my job to help them try and understand, then they wouldn't be doing this*" [18, 867].

Participants also emphasise the importance of carrying out research in order to continue to promote their work and build up an evidence-base for their practice. Whilst they highlight the growing momentum for research within the area of psychotherapy in dementia, a number of them suggest that there is a long way to go still in what appears to be an uphill struggle:

Sophie "*I think if enough people are doing it, and if people go around writing it up, then you know we would start to gather an understanding of how the therapy does work, how it can help and what would be the kind of signs that it is helping.., but that's* *not really there yet [] I mean I feel like it's a really important area to promote so I think it's really good, you know, that you're looking at that area* " [10, 480].

Reflecting on the importance of completing research to promote the area of work, a few participants speak about this study in their narratives, stressing the importance of building on existing research and promoting their work. This is mentioned explicitly by some participants in their accounts and also expressed by many during the debriefing process. Interestingly, this may be a significant reason for participants volunteering to take part in this study. Raising awareness and developing research in response to the stigma surrounding the work perhaps also enables participants to build a stronger identity and sense of who they are as therapists.

4.4.3 Those Groundhog Day Moments

This sub-theme aims to capture the impact that clients' memory difficulties have on the therapist and therapy as experienced by participants. The majority of participants made reference to the complications that memory difficulties caused in the therapy. One of the difficult aspects of the work, as Rebecca highlights, is that often clients might not be able to remember the content of the therapy from session to session thus making it difficult to work on specific issues or to get clients to work on issues between sessions:

Rebecca "*I think like another tension or another interesting area is.. when you would sort of work with someone and be actively listening to them and feeding back ideas to them but that they might not be able to remember between sessions*" [2, 94].

This might be particularly challenging for Rebecca, compared with other participants, who emphasises, in an earlier extract, how she bases her work on a CBT model. It could be assumed that this model is more content led and relies heavily on actively working on issues in between sessions.

As a consequence of not remembering sessions the work comes across as being repetitive for participants at times. Consequently participants possibly experience the work as very frustrating and difficult. Sophie describes her work with one client in which the sessions had become very repetitive each week with the same story which she was aware was very different from her own reality.

Sophie "*It was a bit of a kind of groundhog day [both laugh] experience in that she'd come back again the next week and we'd go through the same thing again and I felt a bit like you know I was patching her up and sending her out there and that she'd just begin to fall apart again when she was on her own*" [3, 146].

It could be envisaged that this "groundhog day" experience is a frustrating and disempowering one for Sophie in which she repeatedly tries to help her client yet knowing that it will come to no avail. Sophie's reference to "patching her up and sending her out there" is reminiscent of a wartime experience in which soldiers are temporarily healed and sent back out to fight despite the unlikelihood of survival. As such, Sophie's experience of the work could be likened to a battle in which she is perhaps fighting against the challenge that memory difficulties in dementia present. Sophie additionally describes her struggle to remain compassionate and empathic towards her clients in the face of the repetitive nature of the work. These aspects could be considered to be fundamental qualities of a therapist and so perhaps part of the battle that Sophie is experiencing could be in maintaining her identity as a compassionate and empathic therapist in the face of these difficulties. Reflecting on the completion of a different piece of work Sophie expresses a sense of relief at ending:

Sophie "*..also a kind of relief though that you know [sighs] I won't have to hear about it anymore...That in a way you're going to be saved from something, protected from something that was pretty unbearable and relentless and.. yeah those kind of feelings, and it comes to sort of helplessness that you're struggling to work with this huge thing that's actually, you can't take away or make better.. so not having to do that anymore and not having to sort of see the.., trying to think what the word is,.. grim end is in a way a relief*" [8, 378].

Sophie's use of language is interesting here as she describes herself as being "protected" or saved from an "unbearable and relentless" force. This underlines the difficult nature of the work and brings to light the notion of threat once again as reflected upon in previous extracts from Sophie's and other participant accounts. It could be suggested that Sophie needs to be rescued from the ongoing battle she is experiencing in the dementia work and the resultant threat to her identity. As above, it could be interpreted that the threat that Sophie is experiencing relates to her identity as a 'successful' therapist. Thus she experiences relief when the therapy ends and she no longer has to feel threatened. A further interpretation might be that through her work Sophie is forced to face up to the reality of her clients situation and the progressive nature of the dementia condition. Therefore the feeling of relief she describes at ending therapy with her client perhaps relates to her no longer having to hold this reality in her mind. Linking in with the existential theme referred to previously in earlier extracts, this reality could again be a reminder for Sophie of the reality of her own mortality.

A number of participants highlight the confusion that occurs in therapy as a result of clients' cognitive impairment. These confused moments seem to lead to some strange and unreal experiences for participants. In Sophie's account she speaks about a particularly memorable occasion in which her client had attended the therapy appointment early accompanied by another individual who became quite demanding about her client being seen. When Sophie addressed this with her client, her client was not aware of who the individual was or why she had come with her. Sophie describes her experience of this moment in the extract below:

Sophie "*It was all completely.. surreal in a way. She was confused about how this woman had got here, the woman was trying to help her and really kind of actively sort of working really hard to make sure this patient got a good service without actually knowing anything about why she was here or what was going on [both laugh]*" [3, 116].

Brenda also emphasises the strange experiences that can occur as a result of clients memory difficulties. She describes coming into "*funny business*" [15, 710] when sometimes her clients might insist on a particular version of events whilst she experiences something different. For example, one client insisted that he had driven to the therapy whilst Brenda's experience was that he was sitting in his pyjamas and wheelchair in a care home. These experiences can be linked to the idea of different worlds outlined in the previous super-ordinate theme. It could be viewed that in these confused moments participants are pulled into the world of their clients leaving behind their own sense of reality and in turn a part of their own identity.

A couple of participants highlight a particularly difficult aspect of the confusion created by memory difficulties. For some of their clients it was difficult for them to retain the memory of the death of a close relative. This can be seen to be a particularly distressing experience for participants to work with in which they sometimes have to keep reminding their clients of this loss:

Brenda "*It's also very moving when the penny dropped with that lady who hadn't retained her husband's death. Once the penny had dropped it was very difficult to see her crying, it was very difficult to help her through the moment.. that she was recently bereaved, she was bereaved today... but he died two years ago.. so she went instantly from being told that he was dead to the gravestone already being there and having moss on it*" [13, 622].

This experience is clearly a very poignant one for Brenda in which she has to repeatedly support her client through the realisation of the loss of her husband. The image of the gravestone with moss on it is a powerful one and perhaps portrays the strength of Brenda's struggle to manage this situation. Again the existential theme arises here and it could be speculated that this experience brings to light difficult feelings for Brenda in terms of her own mortality. In contrast to similar experiences observed in other participant accounts, given her client's memory impairment she is perhaps forced to confront these mortal aspects alongside her client repeatedly.

It could be inferred from participants' accounts that these experiences of confusion, although at times having a humorous side, are particularly difficult for them. The experiences appear to shake up what they considered to be their own reality leaving them confused and in an unfamiliar place. It could be suggested that in fact participants were having a similar experience to their clients and as such were being drawn into the dementia world - a world delineated by confusion and uncertainty that is disruptive to an individual's sense of self.

4.5 Concluding Remarks

What is noticeable throughout the analysis linking each of the three super-ordinate themes is the concept of identity. Within this concept, an existential theme is interwoven which consequently also traverses all super-ordinate themes. Identity appears to be visible in a number of ways. Firstly, participants' sense of self identity may be under threat from the difficult aspects of the work. In particular, their identity as a 'successful' therapist could be seen to be destabilised by the difficulties encountered in the work, such as when faced with the progressive nature of the disease or its relentlessness. Additionally, participants' own sense of being is perhaps impacted upon in the face of the existential aspects of the work. A good example of this is when participants consider their own mortality when faced with that of their clients. As well as being under threat, their identity might also be considered to be lost at times when they are pulled into the world of their clients. Furthermore, participants appear to be searching for an identity as a therapist in the dementia field surrounded by uncertainty or ambiguity. Finally, it could be argued that it is important to participants to maintain their sense of self identity despite the threat caused by the difficulties they face in the work. Participants are perhaps able to do this through holding on to particular approaches, key figures or client cases and by building their identity through raising awareness and developing research. These factors might enable participants to feel less challenged existentially by giving them a sense of empowerment and purpose.

5.0 Discussion

5.1 Overview

The aim of this study was to gain an in-depth understanding of the experiences of psychological therapists' working psychotherapeutically with individuals with dementia. This was accomplished through analysing semi-structured interviews using IPA. Few studies have explored aspects of experience relating to psychotherapy in the dementia field and it was therefore anticipated that the current study would add to existing knowledge in this area, particularly coming from a qualitative perspective. As outlined in the methodology and procedures chapter, IPA was deemed most appropriate for the research question given that exploring the lived experience and meanings of an individual is central to IPA (Smith & Osborn, 2008) and is consistent with the philosophy of counselling psychology (Strawbridge & Woolfe, 2003). Additionally given that the area is under-researched, and the research question was open in nature, IPA was considered most suitable as it has been recognised as a valuable method of analysis for novel research (Smith & Osborn, 2008). Furthermore IPA has been utilised in a number of studies in the dementia field to date (for example, Clare, 2003; Pearce et al., 2002) and has therefore already demonstrated its value within this area. The aims of the research were to explore how psychological therapists experience their psychotherapeutic work including therapeutic processes, such as the therapeutic relationship, with individuals with dementia.

In this chapter, the findings of this study will be reviewed and explored in the context of existing literature. The implications of the findings will subsequently be considered in light of clinical practice, service provision and training. A critical evaluation of the research study will then take place paying particular attention to methodological considerations including the limitations of the research. The possibilities for future research will additionally be outlined and the section will end with some final reflections and conclusions.

5.2 How do Psychological Therapists Experience their Psychotherapeutic Work?

In this section, the findings will be considered in light of the research questions and will be discussed in relation to existing theory outlined in the literature review. Where unexpected or novel findings have arisen from the analysis, some additional research has been drawn upon in this section which has not previously been reviewed.

5.2.1 Experiences of the Psychotherapeutic Work

Consistent with the more recent psychotherapeutic literature relating to dementia (Mosher-Ashley & Witkowski, 1999), participants emphasised the possibilities of working psychotherapeutically with individuals with dementia. In considering their therapeutic work, participants highlighted a range of psychological models that they perceived to be valuable in their practice with dementia clients, including cognitive behavioural, cognitive analytic, person centred and narrative therapies. This could be considered relatively consistent with the existing research literature examining the effectiveness of psychotherapeutic approaches in dementia (Cheston, 1998). Participants also described how they adapted therapy, for example, by using memory aids, or worked in a flexible way such as by integrating aspects of different models into their practice. Adapting therapy for individuals with dementia has been widely cited in the dementia literature. Kasl-Godley and Gatz (2000), for example, noted several adaptations to therapy when working with individuals with dementia, including structuring sessions, using concrete examples and employing external aids. In employing these aids, participants in the current study were perceived to act as a container for their client's memories. Lipinska (2009), reflecting on her own experience of counselling individuals with dementia, similarly speaks about holding on to her client's memories in such a way. This theme is also reflected in some of the caregiver research (for example, Orona, 1990) which will be expanded upon below. Participants appeared to perceive the main psychological focus in therapy to be around working with their clients' losses and supporting clients through a fragile process of adjustment to the dementia diagnosis. Similarities can be drawn here with these findings and those of Mosher-Ashley and Witkowski (1999). In a quantitative study based in Massachusetts, USA, the experiences of therapists in providing psychotherapy to individuals with dementia were explored. The study established that loss and adjustment were significant aspects of the therapists' work. Additionally participants' experience of client loss and adjustment in the current study is consistent with much of the literature surrounding the experiences of individuals with dementia in which these aspects are central themes (Bartlett & Cheston, 2003; Holst & Hallberg, 2003). Creating a validating and containing environment was also considered to be important to participants, in which their clients could feel listened to and supported. Again these features of therapy are consistent with previous literature in which these aspects are emphasised (Cheston & Bender, 1999).

Participants appeared to express some ambivalence both within and across their accounts as to the benefits of doing psychotherapeutic work with individuals with dementia. On the one hand, the benefits of the work were expressed whilst, on the other hand, suggestions were put forward that it perhaps was not 'proper' therapy and could be carried out by other professionals, such as care staff. One aspect that was perhaps driving this ambivalence was participants' perception that there was a lack of research in the field and that consequently there was not an adequate structure or pathway to follow in the work. As highlighted in the literature review, there has been a wide expansion in the literature exploring psychotherapy with individuals with dementia and a relatively strong evidence-base has been established (Mosher-Ashley & Witkowski, 1999). The evidence-base has been developed relatively slowly in more recent years, however, and what is predominantly absent amongst this literature are randomised-controlled trials. As a result, psychotherapy for dementia has not been well established within NICE guidelines. Consequently, for participants it could be that this lack of development or established pathway creates uncertainty in the work. This idea can be understood by linking in to the concept of identity which will also be explored further in the therapist identity section below. It could be considered that one of the distinctive features of counselling or clinical psychologists' professional identity is their adherence to a scientist-practitioner model (Lane & Corrie, 2006). Research has suggested that the scientist-practitioner model provides psychological therapists with a moral and ethical code which becomes internalised through training (see Abrahamson & Pearlman, 1993; Aspenson et al., 1993). Thus to remain true to this identity as an ethical and effective practitioner it is perceived important to keep informed of research developments (Aspenson et al., 1993). It could be speculated that in the current study given that there has been little research development in more recent times and a lack of research trials which inform NICE guidance and create a pathway for the work, this perhaps presents an ethical dilemma for participants in their practice impacting upon their identity as scientist-practitioners. Therefore conceivably this could be quite anxiety provoking and destabilising for participants evident in the ambivalence and uncertainty they appeared to experience surrounding their work. Participants' sense of identity as scientist-practitioners could be considered to be particularly important in the context of working in settings which are medically driven, such as the NHS, and in fields such as dementia which are predominantly constructed within a medical model. It was evident from participants' accounts that those participants subscribing to a specific model, such as a person-centred approach to dementia, perhaps experienced less uncertainty in their work. In adhering to this approach it is possible that participants were able to move away from the medical model toward a psychosocial understanding of dementia providing them with a pathway for their work which in turn perhaps reinforced their identity as scientist-practitioners. Contrastingly, an interesting question can be raised at this point as to whether the need for structure or a given pathway in the work, as recommended by agencies such as NICE, could be linked to the sample in the current study being mostly clinical psychologists. It could be speculated that given their training and much of their work is within a setting that relies upon the medical model a lack of structure or established guidance in how to conduct the therapeutic work could be particularly destabilising for them. In comparison, it could be speculated that for counselling psychologists there is particular emphasis on critical reflexivity in their practice which consequently might allow the tensions created by the uncertainties of the work to be held more effectively. The sample will be discussed further in the methodological considerations and limitations section below. A further aspect that might have contributed to the uncertainty observed in the work was the progressive nature of dementia which will be explored further in the following process section.

The concept of stigma, such as negative stereotypes or images associated with dementia, was highlighted by participants as a challenging feature of their psychotherapeutic work. Stigma was observed by participants through their interactions with colleagues, other professionals, the clients themselves and at a wider societal level. In response to this stigma, it seemed particularly important for participants, such as Richard or Sian, to promote their work, raising awareness through educating others and carrying out research. Stigma has been well documented in dementia research (Katsuno, 2005), media publications (for example, British Broadcasting Corporation, 2010) and government policies, such as the National Dementia Strategy (Department of Health, 2009). Weaks, McLeod and Wilkinson (2006) conducted a qualitative study of 21 health professionals and underlined the importance of embracing both internal and external stigma in their work with individuals with dementia. Furthermore, in a recent qualitative study carried out by Nolan, McCarron, McCallion and Murphy-Lawless (2006) in Dublin, Ireland, the impact of stigma in dementia was explored in interviews with one individual with dementia, 12 carers and 10 allied health professionals, including one psychologist. Similarly to the findings of the present study, all participants referred to the stigma associated with dementia including negative public images and stereotypes associated with the label. Consequently, a reluctance to engage with individuals with dementia was observed by the participants leading to social isolation for the individual. Corresponding with observations in this study, it was deemed important for participants to address the stigma associated with dementia at a personal, organisational and societal level. This was suggested to be achieved by revising policies to account for these issues, increase resources in services and through greater social inclusion. These ideas are reflected in UK policy in the National Dementia Strategy (Department of Health, 2009) in which raising awareness of dementia in order to challenge public and professional stigma is a key aim.

5.2.2 Experiences of the Therapeutic Process

Apparent in participants' accounts was an exploration of difference in the therapeutic work in comparison to a non-dementia client group. There was a general consensus amongst participants that aspects of the process of therapy were different when working psychotherapeutically with individuals with dementia. This included the pacing and planning of sessions, managing endings and boundary issues. Furthermore sessions were perceived to be focused more on the here and now or in the past rather than the future. Additionally, participants highlighted the importance in their work of setting realistic goals, re-assessing and adjusting goals where necessary and being prepared for goals to change frequently. Differences in the work could be argued to be dependent upon the stage of progression that their clients had reached. This can be considered further in relation to Thompson's (1997) stage model of change of the Alzheimer's disease process. Where clients are in the initial *forgetfulness* phase in which the beginnings of memory impairment first become apparent, the therapeutic process can be considered to be relatively similar to working with other client populations. At this stage only minor adaptations are needed and psychological models can be employed as they might with other client populations. Additionally at this stage, the label of dementia could be viewed as being relatively inconsequential. As the individual progresses to the later *confusional* and *dementia* stages in the model, it could be suggested that participants perhaps become increasingly drawn into adapting the way they might practice in order to accommodate their client's experiences. This is an aspect that will be expanded upon further in the therapist identity section below. It could be argued that the accounts indicate that the difficulties of the work are more evident in these stages. In particular, participants emphasised the difficult and sometimes surreal moments they experienced as a result of their clients' memory impairment. These aspects appeared to create complexity in the therapeutic process and relationship. Specifically participants highlighted the sometimes repetitive nature of the work and the confusion in them that was created by their clients' memory difficulties. These experiences appeared to parallel the confusion and uncertainty that individuals with dementia themselves experience as outlined in Thompson's model.

Tentative parallels can also be drawn between the participants' experiences of therapeutic processes in the current study and the experiences of psychological therapists working in the area of brain injury in which memory impairment is also prevalent. Judd and Wilson (2005), for example, explored the views and experiences of 21 psychological therapists and counsellors in regards to the challenges to forming a therapeutic relationship when working psychotherapeutically with individuals who had sustained a traumatic brain injury. A qualitative technique, namely a data display approach, was employed in the study to examine semi-structured postal questionnaires completed by participants. The main themes of the questionnaire comprised challenges to establishing a therapeutic relationship and strategies to overcome these, differences in the work, expectations of prognosis and possible negative emotional reactions experienced. The analysis consisted of an initial content analysis from which information was derived and used to create matrices of the data display approach. Similarly to the findings in the present study highlighted above, Judd and Wilson (2005) established that the most significant challenge for participants was their clients' memory impairment. This was perceived to obstruct the flow between sessions consequently slowing the therapeutic process and in turn impeding the development of the therapeutic relationship. It was also established in this study that employing memory aids was the most effective strategy to address these challenges. This is consistent with the findings of the current study, highlighted in the above section, in which adapting therapy in response to memory difficulties was emphasised. Furthermore, frustration was identified by Judd and Wilson (2005) as being the most recurrent negative emotion experienced by participants in response to the challenges created by their clients' memory difficulties. This is similar to the current study in which frustration was expressed by several participants in response to the challenging aspects of the work. Sophie, for example, appeared to experience frustration as a result of the repetitive nature of the work created by her clients' memory impairment. Finally, comparable to the present study, supervision was highlighted as a useful means of limiting the effects of these challenges in the work.

5.2.3 Experiences of the Therapeutic Relationship

The therapeutic relationship appeared to be an important part of participants' experience and for the majority was spoken about prior to the subject being raised by the interviewer. This is consistent with the extensive process literature in which the therapeutic relationship is deemed to play a fundamental role in the therapeutic process and outcome of therapy (Bachelor & Horvath, 1999). It could be seen from the narratives that participants worked hard in order to try to understand what their clients were experiencing so that they could make a connection with them. The notion of different worlds was pertinent in the accounts, as was the challenging experience for participants in trying to traverse the divide between their own world and that of their clients. Participants appeared to try to make this connection by employing different strategies such as using their imagination, drawing comparisons with other health conditions and being a detective. It could be considered that these strategies were experienced with varying success. Brenda, for example, perhaps found it more helpful to draw comparison with other health conditions to create a shared understanding with her clients compared to using her imagination. Whilst for Sian being a detective seemed to be particularly rewarding. The therapeutic relationship could be considered to be most significant in enabling participants to reach their clients' world and was perceived to act as a tool to break down barriers in order to reach this different world. Bordin (1979) emphasised the importance of three features of the therapeutic alliance, therapeutic tasks, bonds and goals. What arose from participants' accounts was the importance of the therapeutic bond in the work. Participants highlighted that, often, the content of therapy, such as tasks and goals, was forgotten by their clients as a result of their memory impairments but the relationship was always remembered at an emotional level. Consequently, it was interpreted that emotions acted as a shared language between participants and their clients enabling participants to connect with their clients' world. This is comparable with a validation approach in which the therapy focuses on the emotional experience of the individual (Brooker, 2001). This can, however, be seen to contrast with the findings of Judd and Wilson (2005), in which tasks were identified as being the essential component to the alliance. This difference could be explained given the progressive nature of dementia compared to brain injury. Also perceived to be significant to the therapeutic relationship was being able to view the whole person first and not the dementia condition. Again this seemed to facilitate the connection with the client and their world. This is consistent with Lipinska (2009) who emphasised the importance of holding the individual at the centre of the counselling experience. Furthermore, this idea can be related to the existing person-centred literature in the dementia field. In validation therapy, for example, techniques are employed in order to facilitate acceptance of the individual (Neal & Barton Wright, 2003) and in resolution therapy, acceptance is also emphasised as being an important skill (Goudie, 2003).

The experiences of the therapeutic relationship outlined above significantly contrast with the case study put forward by Greenwood and Loewenthal (1998) in which pre-conceived ideas and a pre-occupation with aspects of the dementia condition became detrimental to the therapeutic relationship. This difference could perhaps be accounted for in light of the more recent expansion of research in the dementia field. Following the rise in literature pertaining to the subjective experiences of individuals with dementia (such as, Clare, 2003; Gillies, 2000; Pearce, Clare & Pistrang, 2002) and psychotherapeutic work for those with dementia (Mosher-Ashley & Witkowski, 1999), it could be that psychological therapists no longer hold the same stigmatised beliefs as they perhaps once did. As highlighted in section 5.2.1 above examining participants' experience of stigma, however, these pre-conceived ideas are clearly still evident in those more distanced to the work. Mosher-Ashley and Witkowski (1999) highlighted in their study that the therapists found it difficult to form relationships with their clients. This also seemed to contrast with the experiences of participants in the present study who, as described above, were able to make connections with their clients at an emotional level despite experiencing some difficulties. Despite this difference, similarity was apparent in relation to the difficult aspects of the work such as clients' ability to remember information and difficulty understanding the role of the therapist. Corresponding with the current study, benefits of the therapeutic work were also observed in terms of increasing understanding and adjustment to the disease. Direct comparison is difficult here, however, as it is not clear what type of therapists were employed in their study.

5.2.4 Therapist Identity

As described in the analysis chapter, therapists' sense of self identity was a significant theme running through all accounts, particularly linked to being a 'successful' therapist. Although this was a novel finding in terms of psychological therapists experiences of their work, identity has been well documented in the dementia literature, particularly in relation to the extent to which the self exists in individuals with dementia (Caddell & Clare, 2010). In order to reflect on the theme of identity evident in participants' accounts, some of this literature will be drawn upon in this section as well as literature pertaining to carers' identity.

The view of identity that is currently prominent within the dementia literature has been taken from a social constructionist perspective. This approach considers identity or sense of self to be developed through social interactions with other people (Cheston & Bender, 1999). The findings in the present study suggested that participants' sense of self identity appeared to be under threat from the difficult aspects of the work that dementia created. Charmaz (1983) was perhaps the first to suggest that chronic illness may pose a direct assault upon the self. In the dementia literature, other researchers have made reference to the notion of threat to self of individuals with dementia (for example, Clare, 2003; Pearce, Clare & Pistrang, 2002). Clare (2003) in a qualitative study interviewed 12 individuals with Alzheimer's disease and their spouses to elicit their understanding of their current situation. Analysing the data using IPA it was established that participants' experiences could be observed on a continuum from a self-maintaining to a self-adjusting stance. It was also highlighted that the threat created by the onset of dementia arising from difficulties in maintaining usual roles and responsibilities made it hard for individuals to preserve a meaningful existence. Similarly to the experience of individuals with dementia themselves, tentative parallels can be drawn with the participants' experiences in the current study. In response to the difficult aspects of the work, such as the progressive and relentless nature of dementia, participants described making personal sacrifices and taking on different roles in their work. Unable to sustain their usual roles as therapists may have resulted in a threat to their identity and an inability to preserve a meaningful existence as therapists. This threat may increase where participants place themselves within a social context in which the demands to provide positive outcomes and to be evidence-based are compelling and where stigma exists.

Parallels can also be drawn between the participants' experiences in this study and the research into couples where one of the dyad has a dementia diagnosis. A good example of such research is O'Shaughnessy, Lee and Lintern (2010) who conducted a qualitative study in which seven spouse caregivers of partners diagnosed with dementia were interviewed about their experiences. It was identified that as a result of the dementia the spouse caregiver's sense of identity was subsumed by the new caregiver role that was adopted. This was experienced as a tension between meeting the needs of their spouse whilst also trying to meet their own needs. Orona (1990), in an earlier qualitative study employing grounded theory explored identity change in ten caregivers of relatives with dementia. In-depth interviews were completed with each individual and participant observations were conducted. Similarly to the above study, Orona (1990) identified patterns of identity loss in the caregivers. Specifically these losses formed a trajectory beginning with initial indicators of identity loss, through to misattribution in which individuals attempted to normalise these indicators and finally mobilisation in which individuals were perceived to take action. In these studies it is evident that, as well as the individuals with dementia themselves experiencing a loss of self, so do those individuals that care for them. Similarly, the findings of this study suggested that participants' identity was lost alongside their clients where they were pulled into the world of their clients, took on different roles and/or made personal sacrifices for their clients. This identity loss was explained by Orona (1990) in terms of the caregiver investing in the relationship with the other. As the dementia progresses and reciprocity is lost the caregiver works both sides of the relationship. Consistently, O'Shaughnessy, Lee and Lintern (2010) emphasised that caregiver identity is defined in relation to their spouse and is lost as the demands of caring take over. As highlighted in the therapeutic process section above, in the current study participants appeared to be increasingly drawn into adapting their practice for their clients as the dementia condition progresses. In doing so it could be argued that participants are experiencing a similar process of working both sides of the relationship leading to an eventual loss of identity.

In the present study, an existential theme was apparent throughout the analysis linking closely with the concept of identity. Participants' sense of being was observed to be under threat when faced with the mortal aspects of the work such as the progressive nature of dementia or client death. Corresponding with this experience, Bender and Cheston (1997) emphasised that working with individuals with dementia is challenging in drawing attention to the therapists' own emotional world, particularly in facing up to inevitable losses. Additionally, this finding could be argued as consistent with the reflections of Semel (2006) in which therapist reactions to their own aging and death were considered to be significant to the counter-transference process when working with older adults including those with dementia. Furthermore, Orona (1990) emphasised the concept of "existential coordinates" (p. 1253), in which certain significant events, for example the diagnosis of a spouse in relation to anticipated future plans to travel upon retirement, may restructure an individual's understanding of the past or future and of their own sense of identity. Whilst this notion was considered in terms of carers' experiences, it may also be beneficial to reflect upon these ideas in light of the participants' experiences in this study. Where participants experienced significant events, for example the death of a client, their existing view of the world may have been altered. Thus it could be speculated that they may need to bring new meaning to their identity and beliefs. In doing so, it could be interpreted that participants may go through a process of self-adjustment. This experience could be argued to be seen, for example, in Brenda's narrative and in the account from Julia where the death of her client enlightens her to the importance of her work and enables her to re-evaluate her existence in the context of the little worries in life.

The work of Becker (1973) can also be usefully drawn upon in considering the existential theme identified in the analysis. In Becker's (1973) book, *The denial of death*, it is postulated that humans are caught up in an existential paradox in which they possess a symbolic identity bringing them out of nature and toward meaning whilst possessing a limited natural physical self in which death is inevitable. Consequently, Becker stipulated that individuals take on an *immortality project* in their symbolic world in order to deny and overcome their mortal fate. In doing so, individuals can adopt a heroic position that brings meaning to their lives and thus defend against the despair and anxiety of death. In relation to the findings of this study, it could be conceived that when faced with the mortal aspects of the work, such as highlighted in Sophie, Julia or Brenda's accounts, participants are brought closer to their own fate and away from the symbolic identity they might have created. Additionally, it could be viewed that taking on the dementia work with its many challenges, as highlighted in the sub-theme 'swimming against the tide', is part of participants' heroic project as suggested by Becker (1973). As such, participants can become part of something meaningful, for example in challenging the societal stigma of dementia, which can continue beyond their own lives. Paradoxically, in adopting this position, it could be argued that participants are left facing the very mortal aspects against which they are defending. Furthermore, given participants experiences of stigma, and perceptions of the societal response to dementia, it could be argued that dementia systems in place at a wider societal level have themselves have been structured in such a way as to avoid confronting the reality of death.

Interesting comparisons can also be made between participants' experiences in this study and the processes identified by Clare (2003). As described above, Clare (2003) identified that in response to the dementia condition individuals were shifting between a self-maintaining position, in which individuals attempted to protect themselves from the threat of dementia, and a self-adjusting position in which individuals attempted to engage with the threat and adjust their sense of self. Similarly, it could be interpreted that participants in the current study were attempting to protect themselves from the threat of dementia through a process of self-maintenance. It was apparent that participants seemed to maintain their identity as therapists through holding on to the positive aspects of the work, such as particular client cases in which they perceived the therapy to have been successful therapy. Identity was also perhaps maintained by identifying with key figures in the dementia field or through identifying with particular psychological models. This could be seen particularly clearly in the accounts of Richard and Sian in relation to Tom Kitwood and the person-centred model.

Additionally, it could be interpreted that participants were maintaining their identity through raising awareness of their work, for example by participating in the present study and educating others, such as care staff. Furthermore, as highlighted in the therapeutic relationship section above, focusing on the therapeutic relationship and connecting on an emotional level with clients whilst discarding the dementia label, conceivably enabled participants to maintain their sense of self identity as therapists by withstanding the more detrimental effects of the dementia. At the same time as this self-maintaining process, participants were perhaps searching for and attempting to define their identity at times where it had been lost through the uncertainty or ambiguity of the work. This was observed in the accounts where participants were evaluating their work or were questioning the differences in the work compared to a non-dementia population, such as when Richard reflects on a particular client case or when Mary considers the differences in the therapeutic relationship. In doing so, it could be argued that participants were experiencing a process of self-adjustment comparable to the process highlighted by Clare (2003) above. As described above, participants also appeared to go through a process of adjustment when faced with the mortal aspects of their work in order to bring new meaning to their existing identity and beliefs.

5.3 Implications of Findings

Some important considerations for clinical practice, service provision and training arose from this study. Participants highlighted numerous examples of the success of their psychotherapeutic work with individuals with dementia, emphasising the value of this type of work in older adult psychology services. What appeared to be absent for participants, however, was an appropriate and consistent pathway to guide this work. This could be addressed, to some extent, through further research and increasingly raising the profile of psychotherapeutic work with individuals diagnosed with dementia. In raising awareness, it may also be possible to continue to abolish the stigma associated with dementia in general and the possibilities for psychotherapeutic work with this client group more specifically.

What was also widely evident in this study was the impact that the work had on participants, particularly relating to their sense of self identity as therapists. Whilst it could be perceived from the accounts that participants had found their own processes for maintaining and adjusting their sense of self in the face of the difficult aspects of the work, it may also be important nonetheless to help facilitate these processes. Self-adjustment could be enhanced through ensuring that adequate support is provided to participants in the form of, for example, clinical supervision and personal therapy. Additionally, in order to maintain a sense of identity in the work it would perhaps be beneficial for participants to attend training and, for peer support, to meet with other psychological therapists who are similarly working with this client group. A number of participants in this study already appeared to value the support of PSIGE, the psychology special interest group for older adults. Therefore encouraging this type of support for all participants would be beneficial. At a wider level, these supports are perhaps relevant aspects to be considered for other psychological therapists working with this client group.

It was evident from the interviews that the majority of participants' enthusiasm for the work began during the early stages of their professional development. Consequently, this could be considered a significant phase in which to engage psychological therapists in psychotherapeutic work within the dementia field. This has important implications for counselling psychology training. As described in the literature review, clinical psychologists appear to dominate in terms of psychotherapeutic work in the dementia field currently although counselling psychologists also work in the area. On a number of clinical psychology training courses trainees rotate through older adult placements and consequently experience this type of work early on in their careers. Given the limited number of counselling psychologists that appear to be working within the area it would be particularly valuable to encourage counselling psychology trainees to take on older adult placements during their professional training. A similar process of rotating through placements would perhaps be helpful and a greater emphasis could be placed on psychotherapeutic work in dementia within the academic component of training courses in order to try to generate greater interest in this domain post-training. Developing the numbers of psychological therapists working within the dementia field would be beneficial in order to progress psychological work with an ever increasing number of individuals with dementia and to challenge the stigma associated with the work. Counselling psychology philosophy recognises the importance of engaging with subjectivity, respecting accounts as valid in their own terms and empowering the individual acknowledging social contexts and discrimination (BPS, 2005). Thus it could be considered that counselling psychologists are particularly well placed for this work. The sample will be discussed further in the subsequent section.

5.4 Methodological Considerations and Limitations of the Current Study

The method utilised in this study led to a rich in-depth account of psychological therapists' experiences of psychotherapy in dementia, consistent with the aims of the research. Each case was analysed methodically to enhance rigour and to allow for an appropriate level of engagement with participants' accounts that could reflect their experiences. Given that IPA is idiographic in nature (Smith et al., 2009), the study does not claim to make generalisations about all psychological therapists' experiences but nonetheless offers a valuable contribution to the currently limited knowledge base in this area of work. The experiences of psychotherapy in dementia have been considered in light of significant themes from nine psychological therapists' accounts. Any implications should therefore be considered in this context. Additionally, in line with the interpretative component of IPA (Smith et al., 2009), the researcher recognises that the findings are based on her own interpretations and consequently others may have identified salience in different themes. Throughout the study, however, the researcher has attempted to ensure transparency regarding the analytic process, providing an audit trail and taking a reflexive position in order to enhance the validity of the study. As highlighted in the methodology and procedures chapter, a second researcher also independently followed the audit trail in order to verify transparency and coherence. The researcher also tried to ensure quality by familiarising herself with IPA through reading and attending a regional IPA group and seeking supervision with an experienced IPA researcher.

Although Smith et al. (2009) advocate in IPA a concentrated focus on a small sample of around three to six participants, it was necessary in this study to satisfy academic stakeholders demanding a larger scale research study for a doctoral thesis. The relatively small sample size in this study, however, still enabled the researcher to explore each case in depth and to ensure that each participant's experience could be heard, thus fulfilling the idiographic commitment of IPA (Smith et al., 2009). A further consideration, in terms of the sample, was that the majority of participants recruited were clinical psychologists with only one describing herself as both a clinical and counselling psychologist. This may have influenced the experiences that were expressed in the accounts and the resultant findings in the study. As considered above, for example, it is possible that the uncertainty expressed by participants surrounding the lack of established pathway in the work was more destabilising for these participants given their profession is perhaps more closely associated with a medical perspective. The difficulties recruiting counselling psychologists into the field of dementia can be understood for a number of reasons. As a profession, counselling psychology is relatively new compared to clinical psychology (Orlans & Van Scoyoc, 2009) and there do not seem to be any requirements to undertake older adult placements through training. Consequently, counselling psychologists are perhaps less likely to develop their experience or interest in the older adult psychology field than clinical psychologists. In turn, only a small proportion of psychological therapists that work in older adult settings currently offer psychotherapeutic work to individuals with dementia. Thus, it can be assumed that counselling psychologists would again make up only a small proportion of those working psychotherapeutically in dementia therefore making recruitment of them problematic, particularly given the time constraints of the research. As outlined in the literature review, there are some counselling psychologists working in this field currently and as the profession grows generally it can be hypothesised that the numbers of counselling psychologists working in the older adult and dementia field will also grow. Additionally it is likely that the demand for psychological therapists, including counselling psychologists, working psychotherapeutically in the dementia field will increase in the future given the political focus currently on the ageing population and with the advancement of pharmacological treatments. Therefore for these reasons the current research study is argued to be worthwhile. Whilst the sample in the current study could be considered to be a limitation given that this is a piece of counselling psychology research, as highlighted in the literature review, a tentative argument can be put forward highlighting the similarities of the two professions and it was suggested that they can be seen on a continuum with overlapping competencies (Bury & Strauss, 2006). Additionally, there has been some speculation that the two professions will merge in the future (Kinderman, 2009). Furthermore, Strawbridge and Woolfe (2003) have highlighted that, given the emphasis in counselling psychology on *being with* clients, the arguments about differences between these two professions become superfluous. What in fact becomes important is what the psychologist brings to the relationship, such as their approach or intentionality (Strawbridge & Woolfe, 2003). Moreover, given that the humanistic models are prevalent within the dementia field (Bender & Cheston, 1997) and as the counselling psychology philosophy is rooted within the humanistic tradition (BPS, 2005) it could be argued that those participants subscribing to humanistic values are not dissimilar to counselling psychologists. Whilst a strong argument can be made for the convergence of the two professions, it has also been interesting to reflect on the findings of the study in light of any distinctions in how therapy is carried out or understood by the two professions, particularly in considering the reflective scientist-practitioner model. As discussed in section 5.2.1 above, for example, for the participants in this study there was a need for structure in the work as a result of the uncertainty created by dementia which seemed to threaten their sense of identity as scientist-practitioners. It could be speculated that counselling psychologists may have experienced this uncertainty differently given the greater emphasis on reflective practice and use of self in therapy. Additionally, counselling psychologists are perhaps used to holding tension in their work, such as between the more positivist and humanistic ideas (Bury & Strauss, 2006), and therefore they might be more able to manage the uncertainties of the dementia work and embrace the nuances that the work creates. Alternatively, given that the professional identity of counselling psychology could be perceived as relatively underdeveloped compared to its clinical counterpart, it could also be speculated that working with dementia might also lead to an increased sense of threat to identity for counselling psychologists.

Given that the pilot study ran smoothly and the participant did not express any difficulty with the interview questions, only minor amendments were made to the interview schedule. For a minority of participants, however, there were unexpectedly some difficulties expressed in answering the questions. As described in the reflexivity section of the methodology and procedures chapter, for Margaret, there seemed to be some anxiety in responding to the question regarding her experiences of process in therapy and she emphasised that this was not the type of language she was used to. Additionally, Mary found it difficult to understand some of the questions and Kerry reported after her interview that she found it difficult at times to hold the questions in mind. Perhaps, therefore, it would have been helpful to have provided specific information on the information sheet regarding the topic areas of the interview questions so that participants could have reflected on them prior to the interviews. On the whole, however, participants did not have difficulty answering the questions and prompts were provided where necessary. The questions were kept open and the researcher followed up interesting areas where needed. At the end of the interview, a few participants commented upon aspects that had not been covered during the interview. This enabled unanticipated areas of participants' experience to be followed up. An additional consideration, in terms of the interviews, was the location in which they were held. The majority of the interviews were held at the participants' workplaces. Whilst on the one hand, being in the environment in which they worked may have facilitated participants' ability to access their experiences, they may, on the other hand, have been more constrained in what they felt able to say, despite the reassurance of anonymity. In particular, participants may not have felt able to convey aspects of their experiences relating to their workplace or the NHS more generally.

As discussed in the reflexive section found in the methodology and procedures chapter, it is also relevant to acknowledge here that my own experience, assumptions and beliefs will inevitably have shaped the way in which the participants' experiences have been understood.

5.5 Suggestions for Future Research

Given that there is limited research into the experiences of psychological therapists working psychotherapeutically in dementia, and a limited evidence-base for psychotherapy in dementia more generally, there are many possibilities for further research to develop the knowledge base in both areas. This study has been valuable in highlighting the experience of psychological therapists working psychotherapeutically with individuals with dementia. It would, therefore, be useful to replicate this study to strengthen these findings and to build a more extensive picture of this work. In particular, one of the key findings from this research study was the impact of dementia on psychological therapists' sense of self identity in their therapeutic work. It could, therefore, be beneficial to carry out a further qualitative study to explore this phenomenon in more detail. Given the particular richness of the pilot interview with Brenda and the concept of threat that was strongly apparent in her account, it might also have been interesting to have completed a series of interviews with her in the form of a single case study design to explore this idea in more depth. Although participants found it difficult to differentiate between their experiences of working with different forms of dementia in this study, it would be interesting to explore the experiences of working psychotherapeutically with individuals with frontal temporal dementia. This form of dementia is accompanied by considerable personality changes (McKeith & Fairbairn, 2001) thus the experience of psychological therapists working with this client group could be very different. Although this was not the intention of the current study, the study could be critiqued in that it did not attend to the experiences of the individuals with dementia themselves and as a result did not provide a direct voice for this group. It would be valuable, therefore, to replicate this study to explore the experiences of individuals with dementia in undergoing therapy or to perhaps perform a comparative study of client and therapist experiences. Furthermore, it would be valuable to establish exactly how many counselling psychologists are currently working within the dementia field in order to develop our understanding of how well the profession is represented in this area. Additionally, replicating this study with counselling psychologists in order to research their experience more specifically would be valuable in increasing relevance to the counselling psychology profession.

5.6 Final Reflections

Reflecting on my personal journey through the research process my experiences can be likened to the hermeneutic circle of the research process described by Smith et al. (2009). In this context, the researcher enters the circle at one point influenced by preconceptions and prior experiences and beliefs. The researcher may not be fully aware of all these prior conceptions but will acknowledge or bracket them where possible. Holding these preconceptions the researcher moves round the circle encountering and engaging with a research participant. Moving back to the initial position, the researcher analyses the data still influenced by his or her pre-conceptions. At this point, however, the researcher is now also altered irreversibly by this new encounter. As outlined in the reflexivity section of the methodology and procedures chapter, I initially came from a position in which I had assumed difference in the psychotherapeutic work both in terms of comparison to a non-dementia population and within the different dementia subsets and had additionally considered *doing psychotherapy* with individuals with dementia. Consequently these pre-conceptions might have shaped the formation of the research questions, interview process and my initial thinking in the literature review on working with particular psychological models in the dementia field. Moving round the hermeneutic circle during the course of the research process, these pre-conceptions became more widely apparent to me as I encountered and engaged with each participant and their narrative. Consequently, as I have engaged in this process I have moved toward a more questioning stance of difference and have adopted a more flexible position as to what might constitute psychotherapeutic engagement influenced by the experiences of the participants. Additionally, in moving around the hermeneutic circle for the first time the notion of threat became apparent in my encounter with the first participant, Brenda. This concept so strongly evident in Brenda's account was a surprising finding for me. It was consequently difficult for me to bracket this idea during my encounters with the latter accounts. This could have therefore influenced my interpretations of the successive narratives. The concept of threat to identity was an unanticipated finding emerging from the accounts and it is, therefore, deemed important in the interests of transparency to acknowledge this difficulty here. However, having an awareness of this influence during the analytic process hopefully enabled me to engage enough with each subsequent participant's narrative in order to facilitate a process of bracketing. It is hoped that providing a transparent audit trail and a high proportion of verbatim extracts in the analysis enables the reader to consider the interpretations to be grounded in the data.

The process of analysing the data and writing up the findings posed a number of challenges for me. It felt difficult at times, for example, to negotiate my own interpretations as the researcher of the participants' interpretation of their experience particularly where they were also making interpretations of their clients' experiences. Additionally, given the value and enthusiasm that the majority of participants seemed to hold for this study in building on existing research and promoting their work, it felt particularly important to represent their experience as accurately as possible and in a positive light. The issue of representing participants authentically has been observed to be a source of frequent anxiety for qualitative researchers (Coyle, 2007). Compounding this feeling, given that the more negative aspects of the work were so apparent it seemed a particularly delicate area to negotiate. Conversely, I am very grateful to my participants for their enthusiasm for their psychotherapeutic work in dementia which has kept me inspired throughout the analytic process.

Finally, given the challenges experienced by participants of their psychotherapeutic work with individuals diagnosed with dementia which have predominated the findings of this study, I have chosen to end this section with a quotation from Richard's account which I perceive to not only be a positive way of considering the future of psychotherapeutic work in dementia but also appears to capture Husserl's phenomenological ideas of responding to the *taken for granted* aspects of experience and attempting to focus on the particular in its own right (Smith et al., 2009).

Richard "*You know you don't always have to have the all encompassing all singing all dancing wonderful package of care... from diagnosis through to end of life care. Actually, it's also important what we do right here and right now and even if that's only an hour for now and then you don't see people again, it's also important how we go about that and we can do that in a therapeutically worthwhile sort of way that makes that an experience that is worth people's while having*" [12, 559].

5.7 Conclusions

It is hoped that this study has made an important contribution to knowledge in the dementia research field regarding the experiences of psychological therapists working psychotherapeutically with individuals with dementia, including experiences of therapeutic process and relationship. Employing IPA has facilitated the development of a rich, in depth account of participants' experiences that is consistent with existing literature in the area of dementia but has allowed for the emergence of novel areas. Three super-ordinate themes emerged from the accounts representing participants' subjective experiences: Considering the Psychotherapeutic Work; Bridging between Two Worlds; and The Detrimental Effect of Dementia on the Therapist and the Therapeutic Work. In their psychotherapeutic work, participants highlighted a range of psychological models that they employed in their practice and emphasised a number of adaptations to their work. Working with loss and adjustment appeared to be significant and the issue of stigma was considered to be a challenging aspect of the work. Furthermore, ambivalence about the work was apparent in participants' accounts and an exploration of difference regarding the therapeutic process was evident, seemingly linked to the progressive nature of dementia. The therapeutic relationship was perceived to be particularly important for participants in order to connect with the clients' world with emotions representing a shared language between participants and their clients. Of particular interest, the concept of identity arose from the narratives. Dementia was conceived to be a threat to participants' identity preventing them from sustaining their usual roles and preserving their existence as therapists. Participants' sense of being was also perhaps impacted upon by the existential aspects of the work. Finally, it could be interpreted that a process of self-maintenance and self-adjustment in the face of threat to identity arising from the dementia work was apparent. In addition to adding to the knowledge base in the dementia area generally, this study has also been valuable in contributing to the expanding literature employing IPA in the dementia field. Through developing an understanding of the dementia phenomenon in this way it may be possible to build a substantial and informative research picture.

As well as making an important contribution to dementia research as outlined above, this study has also contributed to the counselling psychology field. There are currently some counselling psychologists working within the dementia domain and it is possible that they will do so increasingly in the future given the combination of pharmacological advancements, the ageing population and an increased government focus on dementia. Therefore, this study is valuable for these psychologists in developing a greater understanding of the experience of working psychotherapeutically with individuals with dementia which in turn can inform their clinical practice. Paying particular attention to the experience of therapeutic processes including the therapeutic relationship, a fundamental aspect of counselling psychology (Strawbridge & Woolfe, 2003), is also informative for clinical practice. Given the dearth of counselling psychology literature in the dementia field currently this study provides a useful first step towards challenging this deficiency and raising the profile of psychotherapeutic work in dementia for counselling psychologists currently outside this field. Therefore dissemination of the findings from this study, for example, through publication or attending conferences, will be particularly important.

Word Count – 45,000

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7.0 Appendices

Appendix 1 – Recruitment Poster

Appendix 2 – Participant Information Sheet

Appendix 3 – Participant Consent Form

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Appendix 10 – Full Annotated Participant Transcript

Appendix 11 – Master Theme Table

Appendix 12 – Cross Case Master Theme Table

Appendix 1: Recruitment Poster

LONDON
metropolitan
university

Participants required for research study

Are you a psychological therapist working with individuals with dementia?

Would you be willing to share your experiences in a confidential setting?

If yes to both these questions then please read on...

I am currently recruiting participants for my doctoral thesis as part of a professional doctorate in counselling psychology at London Metropolitan University. The research will be investigating the experiences of psychological therapists working psychotherapeutically with individuals with dementia.

The study will involve a one hour interview in which you will be asked to share your experiences.

University ethical approval has been gained for this study.

If you would like to find out more information about this study please contact **Philippa Blythe** on telephone number **07504 926184** or by email at **pmb0035@londonmet.ac.uk**

Appendix 2: Participant Information Sheet

Participant Information Sheet – Therapists experiences of working with dementia

Dear Participant,

You are invited to take part in a research study exploring therapists' experiences of working psychotherapeutically with individuals diagnosed with Alzheimer's disease. Before you decide, please read this information sheet carefully so that you understand the purpose of the research and what will be involved. It may be helpful to discuss the research study with someone else before you reach your decision. Please contact the researcher if there is anything you do not understand or if you have any questions about the research.

Purpose of research:
The research study is being carried out as part of a professional doctorate in counselling psychology at London Metropolitan University. The research aims to explore the experiences of psychological therapists' working therapeutically within the field of dementia which is why you have been chosen to take part in the study. Your views and experiences are important.

Taking part:
It is up to you whether you wish to take part in the study or not. If you do wish to take part, you will be requested to sign a consent form. You are entitled to withdraw from the study at any time without giving a reason.

The study will involve taking part in an audio-recorded conversation, in which you will be asked about your experiences. It is anticipated to take one hour of your time. It will be held in a confidential setting either at the university or at a pre-arranged public location and will be conducted by the researcher, Philippa Blythe. I will be asking you to tell me about your experiences of working psychotherapeutically with individuals with Alzheimer's disease. Though the content of the interviews are not intended to be highly emotive, if at any point you feel upset, you will not be pressurised to continue.

Confidentiality:
Personal details and information you provide throughout the study will remain confidential and in the possession of the researcher. The only exception to confidentiality would be if any information is disclosed suggesting illegal activity or in which harm may come to yourself or other in accordance with the BPS code of ethics.

As the information is being collected as part of a doctoral thesis, an academic tutor and markers will have access to it, though it will be kept anonymous. The results of the research may also be published in an academic journal and again the information you provide will remain completely anonymous. Data will be kept by the university for a period of five years and will then be destroyed.

Making a complaint:
If you would like to make a complaint concerning your treatment during any part of this study, you may contact my Director of Studies at London Metropolitan University, Dr Mark Donati on 020 73201110 / m.donati@londonmet.ac.uk.

After reading this information sheet, if you would like to take part in the study, please contact the researcher, Philippa Blythe on 07504 926184 / pmb0035@londonmet.ac.uk.

Thank you very much for your time.

Yours sincerely,
Philippa Blythe

Appendix 3: Participant Consent Form

LONDON
metropolitan
university

Participant Consent Form – Therapists experiences of working with dementia

Please complete this form, printing and signing your name and writing the date at the bottom of the page. If you require further assistance with this, please do not hesitate to ask.

Please circle
Yes or No

1.) Have you read and understood the information sheet given to you? **Yes / No**

2.) Have you been given the opportunity to ask questions and discuss this study? **Yes / No**

3.) Are you happy with the answers given? **Yes / No**

4.) Do you understand that you are free to decline participation in this study or you can withdraw from the study at any time without giving a reason? **Yes / No**

5.) Do you understand that the information you provide will remain confidential and anonymous unless the information disclosed is illegal or likely to cause harm to self or other? **Yes / No**

6.) Do you agree that the researcher may audio-record the conversation? **Yes / No**

7.) Do you agree that the researcher may use quotations from the conversation when writing up the research? **Yes / No**

8.) Do you agree to take part in the above study? **Yes / No**

....	....	....
Participant Name	Signature	Date
....	....	....
Researcher Name	Signature	Date

Appendix 4: Participant Support Information Sheet

Participant Support Information Sheet

Alzheimer's Society – www.alzheimers.org.uk

The British Psychological Society – www.bps.org.uk /enquiries@bps.org.uk/
0116 254 9568

Citizens Advice Bureau – www.citizensadvice.org.uk

Department of Health – www.dh.gov.uk / 020 7210 4850

Mind – National association for mental health – www.mind.org.uk / 0845 766 0163

NHS Direct – www.nhsdirect.nhs.uk / 0845 4647

PSIGE – Psychology specialists working with older people – www.psige.org

Samaritans – www.samaritans.org / jo@samaritans.org / 08457 90 90 90

Appendix 5: Interview Schedule

Interview Schedule

1.) Can you tell me about the setting you work in and how long you have worked in this setting?

2.) How have you come to work with individuals diagnosed with Alzheimer's Disease?

PROMPT – *Was there anything that you think has attracted you personally or professionally to working with this particular group?*

3.) Can you tell me about your own experience of what is it like working with individuals diagnosed with Alzheimer's Disease as a psychological therapist?

PROMPTS –

- ☐ *Approaches used*
- ☐ *Adaptations*
- ☐ *Differences*
- ☐ *Challenges*
- ☐ *Rewards*
- *What was that like?*
- *How does that feel?*
- *Could you say more about that?*

4.) Can you tell me about your own experience of the therapeutic process in therapy, including the therapeutic relationship, when working with individuals diagnosed with Alzheimer's Disease?

PROMPTS –

- ☐ *Change*
- ☐ *Beginnings*
- ☐ *Endings*
- ☐ *Process Issues*
- ☐ *Differences*
- ☐ *Challenges*
- ☐ *Rewards*
- *What was that like?*
- *How does that feel?*
- *Could you say more about that?*

5.a) What issues are important to furthering understanding of psychological therapy for individuals with dementia and the therapeutic process?

b) What are your hopes/concerns for the therapeutic work?

6.) Is there anything else that you expected me to ask you in this interview that you feel is important and would like to share?

Appendix 6: Reflective Diary Example Extract

Initial reflections immediately following each interview...

Pilot – Sense of loneliness/isolation – non-stop talking would have continued for longer – seemed to be exciting daytrip! Fascinating stories – difficult situations arising during the work (idea of threat/battle). Found really interesting – use of language. Struggle between listening – thoughts on themes § holding follow up questions whilst keeping track of time.

Two – Seemed very theoretically driven focused on neuro. Very surfacy answers on first impression – difficult to get to true experience/feelings – needed to draw out personal experiences. ? due to clinical psychology background. Felt somewhat leading in some follow up questions. Related to participant with her early experiences of care work.

Three – Some valuable insights – similarities with other participants. Seemed unconfident with therapeutic relationship / process questions - ? her understanding of counselling psychology. Seemed to struggle with idea of 'your experience'. Struggled to think of examples to support what she was saying. Appeared to be less differentiation between diagnostic labels of dementia - ? is there a difference between Alzheimer's § dementia. Appeared rushed to finish due to another appointment.

Four – Seemed more able to reflect on her experience than last two. Ideas about combining diagnostic assessment § therapy – being person-centred. Link to pilot - theme of dementia as threat. Seemed to really care about her clients - felt warmth § positivity throughout interview. Was able to follow up experience more easily.

Five – Experienced as slightly odd at first but then really likeable. Really enjoyed interview – appeared very knowledgeable § passionate about working in dementia field. Seemed to be at a personal § professional level – strongly influenced by one case example. Again ? no difference between Alzheimer's § dementia. Interview interrupted by weather!

Six – Appeared really caring towards clients § cares about her job. Passionate about psychotherapy in dementia field. Negative impact of client work apparent. Felt more easy/confident to follow up questions in interview around what it was like/how she felt.

Seven – Appeared very enthusiastic about her work § person-centred model. Could have spoken all day! Was very keen for study to be published § seems to publish a lot her self. Had problem with her back – kept standing up during interview. Seemed determined to do interview despite feeling unwell!

Eight – Again very enthusiastic about her work especially dance movement group. Interpreted some questions differently to other participants § didn't fully understand. Seemed isolated in her knowledge e.g. around other professionals already working psychotherapeutically in dementia / services. Gave me a copy of Sinason article which she reported made her cry.

Nine – Interview much shorter than others. Seemed to speak somewhat differently compared to others about her experiences. Due to leave her job the following day ? heart not in it anymore / already moved on / protecting self. Made suggestions for interview – perhaps have a focus group or have ongoing follow up questions – found it difficult to hold questions in mind at times. Perhaps some parallels with my own experience of completing interviews?

Appendix 7: Letter of Ethical Approval from NHS Research Ethics Committee

NHS
National Research Ethics Service
Brent Medical Ethics Committee
Room 019, Level 7 Maternity Block
Northwick Park Hospital
Watford Road
Harrow
Middlesex
HA1 3UJ

Telephone: 020 8869 3805
Facsimile: 020 8869 5222

03 August 2009

Miss Philippa Blythe
Trainee Counselling Psychologist
London Metropolitan University (student)
LMU, City Campus
Calcutta House, Old Castle Street,
London,
E1 7NT

Dear Miss Blythe

Study Title:	**A qualitative study exploring psychological therapists experiences of providing psychological therapy to individuals with dementia.**
REC reference number:	**09/H0717/48**
Protocol number:	**1**

The Research Ethics Committee reviewed the above application at the meeting held on 27 July 2009. Thank you for attending to discuss the study.

Ethical opinion

In discussion, the Committee noted the following ethical issues.

The committee wanted to know who the second researcher was as they had not been named on the IRAS application Form and you replied that you had not decided who this person would be but it would be a colleague at the University. The Chair asked you to confirm this before the study started and to provide their CV for our records and a condition of the favourable opinion.

The committee pointed out that the Sponsor's insurance was due to run out and requested an updated insurance certificate be sent when it was available which you agreed to do.

The committee noted that there were only 12 participants and as you intended to use direct quotes it would be good practice to allow the participants to review the quotes before publication to give them an opportunity to withdraw quotes in case they change their minds and you agreed to do this. You also confirmed that the data would be stored on encrypted personal computer.

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

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

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

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

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk. Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

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

1. **To confirm the name of the second researcher and to provide their CV for our records.**

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
CV for Dr Mark Donati		
Covering Letter		17 June 2009
Protocol	1	17 June 2009
Investigator CV		17 June 2009
Application	1	17 June 2009
CV for Jill Mytton		
Participant Consent Form	1	17 June 2009
Participant Information Sheet	1	17 June 2009
Advertisement	1	17 June 2009
Interview Schedules/Topic Guides	2	17 June 2009
Doctoral Research Thesis Marking Criteria		05 March 2009
Evidence of professional insurance		05 October 2008
CV for Zakia Mahmood		

Membership of the Committee

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

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

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

- ☐ Notifying substantial amendments
- ☐ Adding new sites and investigators
- ☐ Progress and safety reports
- ☐ Notifying the end of the study

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

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

09/H0717/48 **Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

Dr K. Anie
Vice-Chair

Email: Mona.Shah@nwlh.nhs.uk

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*
"After ethical review – guidance for researchers" [SL-AR2 for other studies]

Copy to:

Dr Mark Donati
Senior Lecturer in Counselling Psychology
LMU, City Campus, Room CS1-08
Calcutta House, Old Castle Street
London, E1 7NT

Mr Anthony Davies
Oxleas NHS Foundation Trust
R & D Office
Pinewood House, Pine Place
Dartford, Kent
DA2 7WG

Brent Medical Ethics Committee

Attendance at Committee meeting on 27 July 2009

Committee Members:

Name	*Profession*	*Present*	*Notes*
Mr Suresh Akula	Retired Civil Servant	Yes	
Mr Sinan Alsaffar	Pharmacist	Yes	
Dr Kofi A Anie	Clinical Psychologist	Yes	
Mrs Sunder Chita	Manager	Yes	
Dr C Bernard Colaco	Consultant Rheumatologist	No	
Dr Neeta Ghosh-Chowdhury	General Practitioner	Yes	
Dr Sanober Haque	Doctor of Medicine	No	
Ms Homa Syeda Hasan	Bioethics Adviser	Yes	
Mr Maurice Hoffman	Teacher	Yes	
Mr Paul James	Chief Audiologist	No	
Dr Wing May Kong	Consultant Physician and Honorary Senior Lecturer	No	
Mrs Shaheda Lakha	Oncology and Clinical Trials Pharmacist	No	
Mr Adeyemi Olagbegi	Clinical Pharmacology Study Data Manager	No	
Mr Howard Woolfson	Senior Exam Invigilator	Yes	
Miss Ourania Xeniou	Clinical Trial Site Manager	Yes	
Miss Zainab Yate	Research & Performance Officer	No	

Also in attendance:

Name	*Position (or reason for attending)*
Mrs Mona Shah	Senior Coordinator

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NHS

National Research Ethics Service

Brent Medical Ethics Committee
Room 019, Level 7 Maternity Block
Northwick Park Hospital
Watford Road
Harrow
Middlesex
HA1 3UJ

Telephone: 020 8869 3805
Facsimile: 020 8869 5222

Appendix 8: Letter of Confirmation for Receipt of Additional Documentations to NHS Research Ethics Committee

28 October 2009

Miss Philippa Blythe
Trainee Counselling Psychologist
London Metropolitan University (student)
LMU, City Campus
Calcutta House, Old Castle Street,
London,
E1 7NT

Dear Miss Blythe

Full title of study:	**A qualitative study exploring psychological therapists experiences of providing psychological therapy to individuals with dementia.**
REC reference number:	**09/H0717/48**
Protocol number:	**1**

Thank you for your letter of 16 September 2009. I can confirm the REC has received the documents listed below as evidence of compliance with the approval conditions detailed in our letter dated 27 July 2009. Please note these documents are for information only and have not been reviewed by the committee.

Documents received

The documents received were as follows:

Document	*Version*	*Date*
CV for Zakia Mahmood		
Sponsor Insurance certificate		04 October 2009

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

09/H0717/48	**Please quote this number on all correspondence**

Yours sincerely

Mrs Mona Shah
Committee Co-ordinator

E-mail: Mona.Shah@nwlh.nhs.uk

This Research Ethics Committee is an advisory committee to London Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

Copy to:

Dr Mark Donati
Senior Lecturer in Counselling Psychology
LMU, City Campus, Room CS1-08
Calcutta House, Old Castle Street
London, E1 7NT

Mr Anthony Davies
Oxleas NHS Foundation Trust
R & D Office
Pinewood House, Pine Place
Dartford, Kent
DA2 7WG

Appendix 9.1: Letter of Confirmation for Research and Development Approval from NHS Trust A

Miss Philippa Blythe
Trainee Counselling Psychologist
London Metropolitan University (student)
LMU, City Campus
Calcutta House, Old Castle Street
London
E1 7NT

08-September2009 ref- EJS/eb

Dear Miss Blythe

Title of Study: **Qualitative study exploring psychological therapists experiences of providing psychological therapy to individuals with dementia**
REC reference number: **09/H0717/48**
Protocol number: 1

I am pleased to confirm that the above study has now received R&D approval, and you may now start your research in Mental Health NHS Trust. May I take this opportunity to remind you that during the course of your research you will be expected to ensure the following:

- **Patient contact:** only trained or supervised researchers who hold the appropriate Trust/NHS contract (honorary or full) with the Trust are allowed contact with the Trust's patients. If any researcher on the study does not hold a contract please contact the R&D office as soon as possible.
- **Informed consent:** original signed consent forms must be kept on file. A copy of the consent form must also be placed in the patient's notes. Research projects are subject to random audit by a member of the R&D office who will ask to see all original signed consent forms.
- **Data protection:** measures must be taken to ensure that patient data is kept confidential in accordance with the Data Protection Act 1998.
- **Health & safety:** all local health & safety regulations where the research is being conducted must be adhered to.
- **Adverse events:** adverse events or suspected misconduct should be reported to the R&D office and the Ethics Committee.
- **Project update:** you will be sent a project update form at regular intervals. Please complete the form and return it to the R&D office.
- **Publications:** it is essential that you inform the R&D office about any publications which result from your research.
- **Ethics:** R&D approval is based on the conditions set out in the favourable opinion letter from the Ethics Committee. If during the lifetime of your research project, you wish to make a revision or amendment to your original submission, please contact both the Ethics Committee and R&D Office as soon as possible.

Please ensure that all members of the research team are aware of their responsibilities as researchers.

We would like to wish you every success with your project

Yours sincerely,

Appendix 9.2: Letter of Confirmation for Research and Development Approval from NHS Trust B

Philippa Blythe
132 Barnfield Gardens
Plumstead Common Road
London
SE18 3QZ

29 November 2010

Dear Miss Blythe,

Research Title:	**A Qualitative study exploring psychological therapists experiences of providing psychological therapy to individuals with dementia**
Principal Investigator:	**Miss Philippa Blythe**
Project reference:	**PF432**
Sponsor:	**Oxleas and City University**

Following various discussions your study has now been awarded research approval. Please remember to quote the above project reference number on any future correspondence relating to this study.

Please note that, in addition to ensuring that the dignity, safety and well-being of participants are given priority at all times by the research team, host site approval is subject to the following conditions:

In addition to ensuring that the dignity, safety and well-being of participants are given priority at all times by the research team, you need to ensure the following:

- The Principal Investigator (PI) must ensure compliance with the research protocol and advise the host of any change(s) (eg. patient recruitment or funding) by following the agreed procedures for notification of amendments. Failure to comply may result in immediate withdrawal of host site approval.
- Under the terms of the Research Governance Framework, the PI is obliged to report any adverse events to the Research Office, as well as the REC, in line with the protocol and sponsor requirements. Adverse events must also be reported in accordance with the Trust Accident/Incident Reporting Procedures.
- The PI must ensure appropriate procedures are in place to action urgent safety measures.
- The PI must ensure the maintenance of a Trial Master File (TMF).

- The PI must ensure that all named staff are compliant with the Data Protection Act, Human Tissue Act 2005, Mental Capacity Act 2005 and all other statutory guidance and legislation (where applicable).

- The PI must comply with the Trust's research auditing and monitoring processes. All investigators involved in ongoing research may be subject to a Trust audit and may be sent an interim project review form to facilitate monitoring of research activity.

- The PI must report any cases of suspected research misconduct and fraud to the Research Office.

- The PI must provide an annual report to the Research Office for all research involving NHS patients, Trust and resources. The PI must also notify the Research Office of any presentations of such research at scientific or professional meetings, or on the event of papers being published and any direct or indirect impacts on patient care. This is vital to ensure the quality and output of the research for your project and the Trust as a whole.

- Patient contact: Only trained or supervised researchers holding a Trust/NHS contract (honorary or substantive) will be allowed to make contact with patients.

- Informed consent: is obtained by the lead or trained researcher according to the requirements of the Research Ethics Committee. The original signed consent form should be kept on file. Informed consent will be monitored by the Trust at intervals and you will be required to provide relevant information.

- Closure Form: On completion of your project a closure form will be sent to you (according to the end date specified on the R & D database), which needs to be returned to the Research Office.

- All research carried out within Mental Health NHS Trust must be in accordance with the principles set out in the Department of Health's Research Governance Framework for Health and Social Care 2005 (2^{nd} edition).

Failure to comply with the conditions and regulations outlined above constitutes research misconduct and the Research Office will take appropriate action immediately.

Please note, however, that this list is by no means exhaustive and remains subject to change in response to new relevant statutory policy and guidance. If you have any queries regarding the above points please contact

Yours sincerely,

Research & Development Director
Chair, Research & Development Committee

Terms and conditions of Approval, version 1.1 29/11/2010

Appendix 9.3: Letter of Confirmation for Research and Development Approval from NHS Trust C

From: @nhs.net
To: philippablythe@hotmail.com
Date: Wed, 11 Nov 2009 10:17:58 +0000
Subject: RE: 0918 research project

Dear Philippa,

Just to confirm that I have received your signed copy of the "Acceptance of responsibility to ensure adherence to agreed research protocol" and this project may commence within.

Any queries please let me know.

regards,

Chair, R&D Group

From: (NHS and Social Care Partnership Trust)
Sent: 02 November 2009 08:51
To: philippa blythe
Subject: 0918 research project

Dear Philippa,

I am pleased to inform that I have just sent you a letter to inform you that this project has just been approved. You need to sign this letter - it basically confirms that you will conduct the project according to trust policy. Once I receive the signed letter I will send you an email confirming that the project can commence - the project should not commence until you receive this email.

Any queries please let me know.

regards,

Chair, R&D committee

Appendix 9.4: Letter of Confirmation for Research and Development Approval from NHS Trust D

Miss Philippa Blythe
Trainee Counselling Psychologist
London Metropolitan University
LMU, City Campus
Calcutta House,
Old Castle Street,
London
E1 7NT

16/12/2009

Dear Miss Blythe,

Our ID: 1289/NOCI/2009
TITLE: A qualitative study exploring psychological therapists experiences of providing psychological therapy to individuals with dementia.

Thank you for your application to the for research governance approval of the above named study.

I am pleased to inform you that the study has been approved, and so may proceed. This approval is valid in the following Organisations:

- **NHS Foundation Trust**

The final list of documents reviewed and approved is as follows:

- NHS R&D Form (submission code: 21440/74279/14/446)
- SSI Form (submission code: 21440/63478/6/655/32072/151900)
- Thesis Proposal (no version control, undated, received 15/12/2009)
- Proposed Interview Schedule (version 2, dated 17/06/2009)
- Participant Information Sheet (version 1, dated 17/06/2009)
- Participant Consent Form (version 1, dated 17/06/2009)
- CV for Miss Philippa Blythe (signed and dated 09/12/2009)
- Evidence of Professional Indemnity Insurance (dated 05/10/2009)
- Brent Medical REC approval letter (signed and dated 03/08/2009)
- Brent Medical REC receipt of evidence of compliance letter (signed and dated 28/10/2009)

Your research governance approval is valid providing you comply with the conditions set out below:

1. You commence your research within one year of the date of this letter. If you do not begin your work within this time, you will be required to resubmit your application.
2. You notify the Consortium Office should you deviate or make changes to the approved documents.
3. You alert the Consortium Office by contacting me, if significant developments occur as the study progresses, whether in relation to the safety of individuals or to scientific direction.
4. You complete and return the standard annual self-report study monitoring form when requested to do so at the end of each financial year. Failure to do this will result in the suspension of research governance approval.

5. You comply fully with the Department of Health Research Governance Framework, and in particular that you ensure that you are aware of and fully discharge your responsibilities in respect to Data Protection, Health and Safety, financial probity, ethics and scientific quality. You should refer in particular to Sections 3.5 and 3.6 of the Research Governance Framework.
6. *You ensure that all information regarding patients or staff remains secure and strictly* confidential at all times. You ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice, Data Protection Act and Human Rights Act. Unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

Good luck with your work.

Yours sincerely,

Appendix 9.5: Letter of Confirmation for Research and Development Approval from NHS Trust E

Miss Philippa Blythe
Trainee Counselling Psychologist
London Metropolitan University (student)
LMU, City Campus
Calcutta House
Old Castle Street
London E1 7NT

20 April 2010

Dear Miss Blythe:

Re: Therapists' experiences of working psychotherapeutically in dementia
R&D ref no. K1003/2

Thank you for sending confirmation of your approval from the ethics committee and submitting your proposed research project, which has now been assessed by the Trust Research Management Group.

I am now happy to inform you that the NHS Foundation Trust has approved this study, therefore NHS Indemnity will extend to any negligence that might occur as a result of or during the course of this project. Should any untoward events occur, it is **essential** that the team member involved contact his/her Trust supervisor and the Research Office immediately. If patients or staff are involved in an incident, you should also contact the Assurance department via Incident.Reporting@ uk

Please note that all NHS and social care research is now subject to the DoH Framework for Research Governance. If you are unfamiliar with the standards contained in this document, or the Trust policies that reinforce them, you can obtain details from the Trust (www. is.uk) or Department of Health (www.doh.gov.uk) websites.

You must inform the Research Office if your project is amended and you need to re-submit it to the ethics committee or if your project terminates. This is necessary to ensure that your indemnity cover is valid and also helps the office to maintain up to date records. For studies where the Trust is acting as sponsor you must send a copy of any monitoring/audit reports to the Research Office.

You are also required to inform the Research Office of any changes to the research team membership, or any changes in the circumstances of researchers that may have an impact on their suitability to conduct research.

Yours sincerely,

Research Director

Appendix 10: Full Annotated Participant Transcript

Participant Four – SOPHIE

EMERGING THEME TITLE /KEYWORDS

I: Um okay so firstly can you tell me about um the setting you work in and how long you've worked in in that setting for?

R: Yeah I've been here for I think seven years the last time I checked [both laugh] um and I kind of work across a range of settings so I do some patients they're kind of outpatient work people living in the community but then I also see some people who are at our day hospital and um also patients on the ward here and it's kind of [sighs] ... a ward for everyone basically who are over the age of 65 who can't live at home anymore so.. often those people who have just reached crisis point and nobody's really sure why so they're brought into hospital for assessment and treatment and often there's the beginnings of dementia behind it and that might have triggered off you know anxiety and depression and all sorts of things on top of that um but you know it's not always the case um we've got a memory clinic here as well I do some work for um [laughs] the way the services are configured is they seem to be constantly changing at the moment so I think ultimately the plan is that all of the patients that actually with memory problems will come through the memory clinic but at the moment the memory clinic only treats straight forward patients with dementia who've got a diagnosis and who are appropriate for medication um and the more complex patients where the diagnosis isn't certain or where there's kind of other mental health problems as well come through the community teams [coughs]..

I: Okay.

R: Does that make sense?

I: Yep thank you um and how have you come to work with individuals er diagnosed with Alzheimer's disease?

R: Um I guess it's part of working with older people um... and the way that the services have been arranged to date is you know that all old people are seen kind of through the same services I know there's kind of plans to separate older people's services out into functional and organic at some point um but at the moment we just see everyone and so kind of a reasonably big chunk of the work is people with dementia or the beginnings of dementia.

I: Mmm are there any sort of personal reasons why you came to work with people with dementia?

R: Mmm... I mean I guess there's always personal reasons involved but um I kind of ended up working with older people because I liked the work basically I had really good experiences of that work when I was training.

I: Mmm.

R: [clears throat] um.. I like it because it's varied and I guess I like it cause yeah you see people with a whole range of problems across a range of services in a way that perhaps you wouldn't in adult services where the service is much bigger and so you might work in a smaller part of the service um.. I you know I do like working with people with dementia it's it's very interesting and challenging um but I couldn't do it as my entire job it has to be a kind of a smallish part of the job

I: Mmm.

R: I think you know a couple of patients a week might be about as much as I can manage I think in terms of the kind of intensive therapy.

I: Mmm.

SETTING

range settings

- diff clients

crisis

uncertainty

secondary conds

dual diagnosis

constant change

straightfwd dem.

complex diags

change plans to services

personal reasons

good exps

varied services problems

only small part

intense

part only

intense therapy

FLEXIBILIT

DIVERSITY

DUAL DIAGNOS - COMPL

UNCERTA

COMPLEX

SERVICE DEVELOP

MOTIVATIO

VARIETY/ FLEXIBILIT - MOTIVA

CHALLENGE INTEREST DETRIMENTA - PERSONAL IMPAC INTENS coming to the window and saying when are you going to see Mrs so and so isn't it her appointment yet and the receptionist was getting quite harassed by this and saying no she's not it's not her appointment until 11 o'clock the transports brought her early so she would go back and sit down and say it is she's been waiting for ages now can someone see her please and you know finally it was the session time and so I saw the patient brought her into the room and sat down and I said I understand you were a bit worried about the session starting on time or something and this lady you were with has been talking to and she was like who is that lady I don't know who she is she came on the bus with me and I don't know who she is and it turned out it was someone who lived in the same block of flats that somehow I don't know had thought that she looked a bit confused and had taken it upon herself to speak to the ambulance driver about where he was bringing her and then I guess a conversation had taken place where she'd said do you want me to come and the patient had said yes and she'd come but she by that point didn't know who she was or what she was doing here and it was all completely.. surreal in a way she was confused about how this woman had got here the woman was trying to help her and really kind of actively sort of working really hard to make sure this patient got a good service without actually knowing anything about why she was here or what was going on [both laugh] and er.. the reason I I think I was thinking of her was because she this patient used to come in very different states and that was a day I guess where she'd been very anxious and confused

confusion
worrying manage confusion
unpredictable
DETRIMEN EFFECT - CONFUSIO
CASE Eg.
PERSONA IMPACT SURREAL MOMEN
UNPRED /UNCER - DIFF

I: Mmm.

R: and so this woman had taken pity on her and tried to look after her and brought her here and that was the kind of effect that she would have on people when she was in that state um and she would sit in the room and more often than not she would tell me exactly the same story that I heard week after week which was that she was very upset because her sister was going to move and she thought her sister was moving next week and her sister was basically the only person that she knew that kind of looked after her and.. um she used to see her everyday and take care of all the kind of practical stuff that she struggled with but her sister wasn't moving there was a plan that one day her sister might move that somehow had been kind of taken in and..

having an effect - state
groundhog day moment
PERS IMPACT
HAVING AFFECT ON - DETRI
GROUNDH DAY MO

I: Mmm.

R: So every week she kind of lived in the fear that the sister was going next week and the sister wasn't going but there was no way she could take that in anymore because you know I think it was part of the kind of.. the world that she lived in now that nothing was safe and nothing was secure and the things that she thought she could rely on and trust were slipping away from her.

talking on affect different world
UNDERST DIFFUS

I: Mmm mmm.

R: Both in terms of her kind of mental abilities and the people around her and the way the world was organised.. um.. and with her it was when she was in that kind of state by the end of the session after we had talked enough about how she was feeling she would leave hopefully in a little bit more of a settled state.

express feeling
CONSIDE WORK USE OF THERAP - CHAN VALIDATIO

I: Mmm.

UNDERSTANDING CLIE WORLD.

R: It was a bit of a kind of groundhog day [both laugh] experience in that she'd come back again the next week and we'd go through the same thing again and I felt a bit like you know I was patching her up and sending her out there and that she'd just begin to fall apart again when she was on her own.

surface level work?
fall apart
GROUNDH DAY MO
DETRIMENTAL EFFECT
PATCHING - IMPACT.

I: Mmm.

? sadness frustration

R: Um which was as much to do with the fact that she was living in [sighs] pretty difficult circumstances on her own in an an inappropriate block block of flats without much support and um.. she really needed some big practical changes to happen.. which I think have happened since and that she is more settled um.. what we did see over a number of weeks was that she did eventually kind of seem to be in a slightly better place and it was partly to do with um a number of other changes going on in her life as well so I couldn't claim it was all to do with the therapy but um there were times when.. especially towards the end she would come in and there was much more of a sense of a kind of coherent person in the room who who did know about what we'd been talking about a bit and did know a bit about what was going on um.. and and could take something in.. um but yeah I guess eventually it was all the change of living arrangements that have probably helped her…. Think the therapy there was as much as you know trying to contain something that was essentially falling apart and unmanageable in terms of her whole life really whilst all the other kind of things got into place to make things better.

uncertainty — rapid changes — boundary therapy — practical changes — changes helped — holding

UNCERTA OUTCO — CONSIDE WORK - VALIDI — CONNECT WORLD / BRIDGIN — CONTAIN - VALID WORK

I: Mmm mmm mmm what was that like for you working with that?

R: [pause 5 seconds] it was difficult, it was frustrating, it was…. It was hard to.. to feel the same level of kind of compassion and empathy.. for a story that you'd heard week after week after week that you knew wasn't true and [laughs] that which seems nothing you can say she could take away that and remember that it wasn't true that her sister wasn't going next week um.. I mean it was it was hard to stay tuned into how she was feeling and not sort of start to glaze over a bit and say yeah okay I've heard this before [laughs] um [pause 5 seconds] but and it was also quite touching though when when you could say something that would sort of hit the spot and help. - MAKING A CONNECTION

feeling compassion — helpless — cannot say anything — small moments

NEGATIV EMOTIO — HELPLES PERSONA IMPACT - DETRIME — SMALL MOME — MOTIVATOR — GROUN DAY

I: Mmm.

R: And you could see if someone who turned up very agitated and very confused not knowing what was going on at all start to kind of ground them self a bit and start to feel a bit more together.

seeing progress — at a more level

SMALL MOME — CONNECTING WORLDS

I: Mmm.

R: Enough to go off out there it was worrying too there you know there was a lot of anxiety in the piece of work and I guess maybe the frustration was partly a response to the anxiety because here is this really worrying situation and this person you're very concerned about.. and you can't physically practically take her and put her in a better place to live where she will be safe um.. and so you have to sort of tolerate that anxiety and I think that can then come out a bit as a frustration as well you know.

making sense — tolerate anx — keeping boundaries

NEGATIV EMOTIO / MAKIN SENSE — DETRIMENTAL EFFECT. - TOLERA (IMPA PERSO

I: Mmm.

R: We've been through this before what we really need to do is get social services involved and the difficult was she used to regularly get professionals like me harassing social services saying come on you need to sort out what's going on with this woman you've got to move her it's not safe and um she's at huge risk and and someone would go and assess her and she'd say no I'm fine I don't want to move there's nothing wrong with me and you know the social worker would say great that's one off the caseload then she's happy where she is and I guess it took a lot of pushing to get people to see beyond that... [sigh].. FRUSTRATION - IN

managing risk — working with others — seeing beyond exterior

MANAG RISK. — WORKI OTHER

I: Um can you say anything else about your your own experience of working with people with Alzheimer's disease?...

R: What it's been like for me personally you mean or different people I've seen?

I: Um what-whatever you sort of want to talk about really in terms of your own experience of of working psychotherapeutically with people with Alzheimer's.

R: Um [pause 6 seconds] well the lady I'm seeing at the moment but…. it's been very.. rewarding to work with and she's someone who's mini mental state is slightly higher.. in the late 20's um she was actually referred with depression.. and that she had noticed some memory problems but the GP thought it was probably the depression and had told her it was the depression and she preferred the idea that it was the depression and so we had a kind of long assessment where we were talking about all the reasons why she was depressed and um and why that might be affecting her memory and then I was quite keen to do a neuropsych assessment because there was something in the way that she was talking that made me think that perhaps there are some more significant memory problems there and so she then did the neuropsych assessment which showed there was quite a bit more impairment than you would expect with depression and um she was someone who would have had very high abilities and it looked like it was beginnings of dementia and from that she got a diagnosis and she also um got some treatment with Aricept this was before they were very strictly enforcing the kind of lower cut off which they have now and um.. and she's doing pretty well since then um it's been a couple of years where she's been on it and I don't think there's been that much deterioration um and I saw her for after she'd had her diagnosis then I saw her for ten sessions to talk about what that meant and then since then she's come back to me so we're talking about two years on um because she's been having a bad patch where she's been getting really anxious.

referral process
confusion re. diagnosis
establishing diagnosis
treatment
prescribing issue
long process
Assisting through

USE OF
CASE E
REWAR
- MOTIVATI
CONFUS
- DIAGN
NEURO
ASSESS
BEING
DETEC
MEDICA
PROCESS

I: Mmm.

R: Um…. And it's hard again it it is hard to tell with her how much she she takes in and consciously remembers about what we talk about… but she visibly in the session kind of feels better after talking about things and does she takes in things that I say.. for the time that we're talking.. you know I don't know what she remembers when she goes home but she does find it beneficial and you know she held in mind this experience as being a good one from two years ago so that when things started falling apart a bit more recently then she was able to say that she wanted to come back and.. um.. she's someone who can really vividly describe how scary it is facing this future where you're no longer going to be able to say what you want or what you need. EXISTENTIAL IMPACT EVALUATING WORK - VALIDITY

in the moment
Hard
benefits in moment
benefit
relationship
Remembering
feeling
experience

IN THE
MOMEN
ASSESSIN
UNDERS
(UNDER
BENEF
REMEMB
NEGATIV
EMOTIO

I: Mmm.

R: And you're relying on other people to look after you and.. and I think she's quite unusual in that respect.. what.. one of things I noticed is… quite often by the time we see people when they get referred to services.. I'd say the majority of cases the patient themselves isn't that concerned about their memory any more and perhaps the memory problems are more obvious and visible to other people so the diagnosis can be more straight forward and.. um.. but the sort of scope for direct talking therapy with them is limited because actually most of the time they just want to go off and carry on with you know their everyday life and very much saying you know nothings wrong I might forget something now and again but then why everyone's making a big deal about it you know just leave me in peace sort of thing and not really wanting to reflect on what's happening and I guess part of that could be an organic lack of insight but probably there's also a psychological defence in there as well um although the

referral issue
straight forward diagnosis
denial
organic

REFERRA
PROCES
DIAGN
AMBIVALE
WORK
UNDER
CASE
WOR

IMPACT – PROTECTION FROM DEM – DETRIMEN

two things work together to protect the person from too much awareness of what's going on.

I: Mmm.

R: Um but then there are a number of people and it's often the kind of higher functioning people I think that… come to us because they're worried that something's wrong with their memory and it can be something quite subtle that maybe other people say 'oh you know we all forget things from time to time don't worry you're fine' and then it's only when we do the more kind of sophisticated testing with them that you can say yes there is a problem actually someone with your abilities wouldn't be doing so badly on some of these tests um.. and I think with those people there is often a real need to talk things through and you know sometimes it will fall onto a straightforward diagnosis and sometimes it won't sometimes it's a question of well it looks like maybe there's something that's a bit unusual that we wouldn't necessarily expect but it it's certainly not clear cut and maybe you should come back in a year if you're still worried about it if maybe it's just you know anxiety or the fact that you've been feeling quite low recently and some you know and some people I've seen over come back two or three times each year before it starts to get clearer.

Uncertainty of diagnosis

Complexity

Progressive

UNCERTA – DIAGNO CONSIDER THE WORK VALIDITY COMPLEX

I: Mmm.

R: this is when you're doing the neuropsych assessment but they've got to live with the worry that something's wrong and there's an idea often that that there is something wrong and it is called dementia and often it's because their sister or their brother or their mother or somebody's had it and so then they're worried that perhaps there's a link perhaps they've got it too and um sometimes it just takes time before it becomes clear um.. and sometimes it already is starting to become clear and.. for those people having the space to talk about their worries about what's ahead of them..

neuropsych assess

having about worries

NEUROPSY ASSESS UNDERSTA CLIENTS W (+EMOT) PROVIDE SPACE. VALIDATIN WORK

I: Mmm.

R: While they're still able to I think is really really important.

I: Mmm.

R: [pause 5 seconds] the woman that I was talking about before the one that can describe… what's ahead ahead of her the whole what she thinks it is she sort of talks about this fear of.. that comes over her it's just like a cold fear that grabs her and just stops her in her tracks and it's when she she's doing something and then she forgets what she's about to do and she looks around and some- something in her hand that she was going to put down or something she was going to pick up and for a second she's forgotten it and and then she just panics because she thinks that's what my life is going to be like um.. she really worries that a bit further down the road she'll go out the house and she'll be lost in the middle of the street like that on her own and people will you know harm her that they'll mug her or do something or you know certainly not help her um.. I think when you're working with people and they can describe that it's… hard to know what to say to help because my God it's terrifying really if I knew that was going to happen to me next year or the year after or.. um… I guess I'd rather be someone without the insight actually.

fear grabbing

worries

putting self in the shoes

without insight

DETRIMEN – DEMENT IMPACT

NEGATIVE EMOTIO

UNDERSTA CLIENT WO

PUTTING IN SHOE

EXISTENTIAL IMPACT – DETRIMENTAL EFFECT

NEGATIVE EMOTION OWN MORTALITY

I: Mmm.

R: pain Um I think it's a very very painful thing to be aware of.

I: Mmm.

R: Something I remember about actually an interesting client I saw ages ago maybe four five years ago saw him for a long time maybe over a year.

CASE Eg.

levels of functioning

I: Mmm.

R: Again you know a really high functioning person who'd got a diagnosis… was very panicky about that initially so I offered him I don't know kind of ten twelve week contract something like that to talk it through and then we extended it and extended it um and by the end of it there had been a real shift in that it was partly to do with his deterioration that he wasn't really that bothered anymore [laughs] I don't it was less about you know the effectiveness of the work there and more about him having moved into a different position where what he then wanted to do was come to the sessions he really enjoyed his sessions but it was partly at that point I think a kind of escape for him that he'd gone from seeing me as someone that he could talk to me about these things that were really worrying him that he couldn't really describe to anyone else and that I could try and help him and to sort of see me in a different light as this kind of young woman that he could sort of escape into this sort of fantasy world really where he could like tell me all these stories from his youth and have to try and bring that side of himself alive again um and he wasn't really talking about the present time at all anymore and the reality you know that he was a elderly man with dementia and I was his therapist it was more you know this kind of flirtatious sort of story teller person with all these he had fascinating stories to tell you know a really interesting life and he was very good at talking about it but then he wasn't really using the sessions for therapy anymore.

negative feeling
flexibility
different position
evaluating work
diff functions of therapy
change relationship
positioning
bringing alive
relationship - role of therapist

Function
negative feeling
flexible
DIVERSE AP
VALIDATIO
changes
position
relation
SUPPOR
CLIENT &
& WORL
ROLE - PE
IMPACT
DEPRIVING
therapist role
CONNECT
CLIENTS W

I: Mmm mmm.

R: And you know I think that reflected in how he'd moved cognitively into a different place where he was less aware of what was happening around him in the present time and less conscious of a future ahead of him and more kind of living into the past in when when he was a kind of colourful character and he'd obviously had a lot of very good times and he was really working hard to keep them alive around him as best he could.

changing times past present & future keeping alive

cognitive change adapts
UNDERS
CONNECT C
WORLD.

I: Mmm and what was that shift like for you working with him?

R: It was a gradual process um…. I think I had the… sort of slow dawning experience that.. that I'd been appreciating the kind of therapist type comments I'd be saying right you know how he was feeling and the kind of things he'd be thinking that he used to really kind of be like yes you know taking on board being glad that somebody had been able to verbalise what he'd been trying to say to sort of feeling like to actually I think he's a bit irritated that I'm trying to talk about his feelings or you know the more difficult side of things when what he really wants me to do is go oh fascinating what did you do then and you know kind of join him in the story telling and enjoying the stories rather than me trying to think well he's telling me about all his interesting amusing times from his youth but that's because perhaps he's so worried about the present and what's going on and it's a kind of escape but he didn't really want to talk about what that was about um so yeah I think it was the experience of sort of starting to feel like perhaps my therapist contributions are less valued here what he wants is a different relationship with me.

focus on feelings thoughts
Shift on feelings
different roles / relationship
telling stories
valuing therapy

Shift of therapist
cog ch
relation
- differ
role
EVALUAT
VALIDITY
WORK
CONNECT
CLIENTS W

I: Mmm mmm.

R: Um.. and then talking in supervision about whether that was just a phase a longer termed piece of work would go through that might take you to a different point or whether that was something that was to do with the path he was taking into dementia to do with the cognitive organic changes and

process of therapy

VALUE SUPERV
therapist process
- path
deme

process therapy
path of dementia
uncertainty

organic changes.

ison/

Compared with non dementia therapy process

rock the boat

person terrifying

something that we wouldn't want to shake too much because I guess in a piece of therapy like that with someone who didn't have dementia you really would want to try and comment on what was happening and you know people use the therapy for all sorts of things and do escape off into worlds of story telling for various reasons along the way through therapy and the therapists job is to help them see what's happening and to understand what the anxieties are that are making them behave like that and so hopefully then they can move to a better place but with someone with dementia I guess you don't want to rock the boat too much because they are doing it for a reason because the person and the future are terrifying and perhaps having that sort of escape and building a world around themselves where they can feel like they're slightly different and maybe in a slightly different kind of fantasy place isn't a bad thing.

Compa - non

Detrimental effect personal impact

Role of therapy

Understanding client world emotion

supervision

I: Mmm.

R: Um so you know I think we talked in supervision about drawing things to a close and kind of leaving things as they were rather than.. trying to change that um.. so.... yeah I'd like to say there was a happy ending ~~but~~ of course there wasn't.

Happy ending leaving things

I: Mmm.

R: Um.. but he was the one who did manage to live at home.. and have a reasonable quality of life until the end I think...

Supervision - value

Detrimental - existential element - death?

Endings - negative uncertain

I: Mmm what was that like um for you the kind of the endings and like the fact that [inaudible few words]?

R: Mmm it's... I don't know it's a mixture of feelings.

Emotions

I: Mmm.

R: It's sad.. I mean it's sad because you're coming to the end of a piece of work but you know it has been a valuable piece of work you know you kind of appreciate that and it's hard because you're not going to necessarily know what happens to the person though I did hear from the rest of the team who were involved um.. and also a kind of relief though that you know [sighs] I won't have to hear about it anymore.

Valuable success

Gratifying

Uncertain - future

Detrimental personal impact

unknown

relief not to hear

demise? ending?

I: Mmm.

R: That in a way you you're going to be saved from something protected from something that was pretty unbearable and relentless and.. yeah those kind of feelings and it comes to sort of helplessness that you're struggling to work with this huge thing that's actually you can't take away or make better um.. so not having to do that anymore and not having to sort of see the.. trying to think what the word is.. grim end is in a way a relief

- Existential - Death

Personal impact

helplessness

huge thing

cannot change not knowing end

Ending

I: Mmm.

R: But you know at the same time you know what's out there you know what's likely to be happening.

Uncertain - knowing

Unknown Existential

I: Mmm.

R: Um... I yeah I suppose there's also.. an awareness of the limits of what you've done and a kind of sadness about that as well I wish I'd been able to do more.

sadness out of control

Limit - Ambivalent / uncertain

I: Mmm.

R: Um.. mind due there always something about whoever you're seeing whether they've got dementia or not [laughs].

comparison non-dem

I: Mmm okay thank you um the next question um touches on things you've said already really but can you tell me about your own experience of the therapeutic process in therapy including the therapeutic relationship when working with individuals with Alzheimer's disease?

Compa - non

→ my leading question?

R: [pause for 5 seconds] Um it's hard to know how to answer that differently from what I've already been saying um [pause for 12 seconds] I suppose your your.. idea of where your working to get to is different.

differences

therape goals

I: Mmm.

R: When someone has dementia.. and the whole process of working to a kind of deeper insight and awareness and self knowledge is basically what you doing in any other therapy is trying to help the person to get to know themselves better get to know more about what's happening to them in terms of their thoughts and feelings and where they've come from and what their about.. but you're very aware that to do that with someone with dementia and partly you're <u>swimming against the tide</u> because you know cognitively they're probably not able to deepen their knowledge of themselves in that way but also that that brings pain and it's a not necessarily going to help them.

similarity – working differently

cognitive factors swim against tide

compar – normal therap

swimm against tide

PROGRESSING

I: Mmm.

R: Um.... although there's a.. you know the other side of that is that there's the benefit of speaking about the unbearable stuff that that you don't flag anywhere else.

pros/cons therapy.

pros/c therap – EXPLOR VALIDI

I: Mmm.

R: Um but it does bring relief to talk about the stuff you're bottling up inside um.. and it does for some people help to try and make sense of that and to try and link that to what you know what what's going on in their life the dementia and all the rest of it.. um but I suppose as a therapist you would keeping a really careful idea on you know is this therapy actually helping or am I sort of pushing this person to face up to something that is not going to help them to face up to and you know are they working really hard not to face up to it and I'm trying to you know you have to really assess what what you're trying to do all the time, I suppose you do that in therapy anyway but keep questioning to yourself is it helping?

making sense of i.e.

re-assess work questioning value of work.

helping make sense

Is it he EVALUATIO

continu assess

QUESTIONING VALIDITY

I: Mmm.

R: [pause for 11 seconds] it's a learn kind of learning process as well because you're you're hearing about a world that you don't know about um.. you can imagine what it might be like to have dementia but obviously you don't know um.

imagine uncertainty putting self in clients' shoes

understo clients

IMAGINE BRIDGE

I: Mmm.

R: I only meet with patients who can really vividly describe it it's kind of fascinating as well um.... with the man that I saw for a year I always really wished I'd tape-recorded the sessions [laughs] because I always think it would be such an interesting piece of work to write up.. um but I didn't [pause 6 seconds] but I guess there's lots of technical issues around that anyway we didn't get to. I think for some people actually the idea that they might be contributing to your knowledge and <u>helping you into peoples minds</u> I think would be a good thing for them they would like that.

tape-record 'have a record'

what stopped her?

getting into the mind.

positive emoti

getting into m world – UNDERS THEIR W CONNE

I: Mmm.

R: The man I'm talking about used to um this wasn't at the beginning of therapy but he at some point along the way he did used to talk about the kind of wish to make a record of things to sort of... <u>have what he was saying mean something to other people</u> he used to want to write a book about it and that kind of thing um so we did kind of talk about how he could use the therapy to make that record but we never really did it [laughs] I think it was more you know that he wished it to leave his mark.

leaving memories behind

leaving a mark

? regret

keeping record

→ part

PERMANANT mak

LINK CLIENTS reco

WORLD fulfillin

clients

I: Mmm okay um what issues are important to furthering understanding of psychological therapy for individuals with um dementia and the therapeutic process?

NHS funding
politics
measuring change
not making people better

EXTERNAL PRESSURE
POLITICS
FUNDING
PATHWAY
EVIDENCE BASE

R: [pause 6 seconds] a lot of political issues.. um in terms of how trusts are funded and organised um I suppose the main thing is it's.. it's not something we know a lot about there isn't a huge evidence base that tells us that therapy with people with dementia is helpful I don't know how you'd measure that change to say show that it was helpful because you can't make people better.. they can't even necessarily fill in a questionnaire that's a where they would say yes it was really helpful for these reasons [laughs].

QUESTIONING VALIDITY
QUESTIONING MEASURE CHANGE

I: Mmm.

self-report
understand
changes
behav
depends

SWIM AGAINST TIDE
Subjective reports

R: Um.. but you know you might see that they've moved to a kind of better position their relatives might report that they're less disturbed at night or less agitated in the daytime and that.. I I guess with different patients your change would be measured in different ways.

I: Mmm.

funding issues
uncharted
new territory
diff funding

EXTERNAL PRESSURE
Exploring unknown
Funding
NO PATHWAY

R: Um.. so it would be hard to pull all that data together to show yes it is a you know useful way of working which means that basically each piece of work you do is kind of exploring something that's not known very much about um.... and I think in the modern current climate I don't know whether that's really something the trusts want to fund.

I: Mmm.

Negative emotion
EXTERNAL PRESSURE

R: You know it's very much about you know doing.. [sighs] short pieces of evidence-based work where you will see that someone's got better.

I: Mmm.

uncertainty - work
future work
getting known
writing up
signs of help

Uncertainty
- future benefit
QUESTIONING
Raising awareness

R: Um… having the luxury of saying well I will see this person I think it could help I'm not quite sure how I'm not sure how long it will take and I [laughs] I'm not sure they'll be able to tell you how it's helped them afterwards you know.. it [sighs] I don't know if that kind of work is going to be funded much in the future in our service or in anyone's services.. I hope it is because I hope you know I think if enough people are doing it and if people go around writing it up then you know we would start to gather an understanding of how the therapy does work how it can help and what would be the kind of signs that it is helping um.. but that's not really there yet.

I: Mmm.

not optimistic
pendulum swing
money

EXTERNAL PRESSURE
Future
Funding
PATHWAY

R: And the kind of stuff for which there is an evidence-base you know CBT and stuff isn't necessarily the best way of working with people with dementia um.. so.. [sighs] so I don't know it doesn't look like a hopeful future for this kind of work at the moment but maybe in a few years time the pendulum will have swung back again and there will be money to put into developing new ways of work rather than sort of marrowing up which is what we are doing at the moment and only doing the things that we know are really valuable and that we can see that.

I: Mmm yeah um what what would be your sort of hopes um or concerns for the therapeutic work you sort of said um a little bit about your hopes there have you got any other hopes or concerns for the work?

people continue work
improve access

continue work
better access

R: [pause 5 seconds] you know the hope is that people will continue to do this kind of work that more services will be able to offer it that maybe services will get better at picking you know the patients who could benefit from it um there's a lot we don't know about how.. how different individuals react to having dementia again you know sort of back to where we started but for a lot of people they wouldn't want this kind of therapy they might benefit from being in a group with other people doing something practical about you know managing memory problems there's all different ways you can do useful work with people but you know a lot of people I don't think would want the kind of personal exploratory type of therapy thinking about what it means that they've got dementia.

I: Mmm.

R: Um but for some people it really really does matter to it really helps them to have that space and… I know our service here isn't necessarily very good at picking out those kinds of people because the way things are now because they've tightened the criteria for giving treatment and making diagnosis the.. the kind of higher functioning people who've got the more subtle memory problems are more likely to be told well lets see what's happened in a years time because at the moment there isn't a serious problem and maybe you know not referred over to us for the talking therapy um but just you know left on their own to sit and wait and see what happens but you know I would hope that services would be able to develop a bit more sophisticated means of picking out the people who might benefit from coming to psychology you know hopefully psychology can have a role in helping develop the memory services.

I: Mmm.

R: But at the moment we're not developing anything because we've got no money so we won't do that it's just the opposite really [laughs].

I: Mmm.

R: Um yeah I mean there's all sorts of potential for kind of new work new understanding but I don't know where the monies going to come from to do it.

I: Mmm okay um and is there anything else that you expected me to ask you in this interview that I haven't asked that you'd like to share?

R: Um [pause 6 seconds] I don't really know I don't think so [laughs]…

I: Okay .. okay thank you very much.

individual basis
forms of work
Benefits
Service criticism
Referral process
Psychology role
developing services
no funding
potential for more

Flexib
CRITERI
FUNDIN
REFERR
PROCE
FIGHTIN
STIGM
ASSE
SERVICE
DEVELO
Fundin
VALIDITY
Poten
FUNDIN

Appendix 11: Master Theme Table

Super-ordinate / Sub Themes	Themes / key words	Page & Line Number
Considering the work	Co-morbidity-depression/anxiety-difficult aspects	1, 12-14
Considering the work/Therapist motivation & values-diverse approach	variety-personal motivation	1, 40-43
Detrimental effect/Personal Impact	challenge	1, 44-46 / 48-49
Considering the work/Diverse approach	Indirect systemic/variety-psychological approach	2, 51-56
Considering the work-Bridging two worlds/Connection individual	Depends on individual	2, 61-64
Detrimental effect/Groundhog day moment	commonality/remembering/memory	2, 65-70
Bridging two worlds/Understanding clients world	remembered/change is at/understanding/emotion	2, 70+
Bridging two worlds/Supporting clients emotional/psychological world	to be held/listened to/psychological role	2, 86-87
Detrimental effect/Groundhog day moment-personal impact	client example/surreal/confusion-memory	2/3, 93+
Detrimental effect/Personal impact	having an effect on people	3, 125
Detrimental effect/Groundhog day moment	repeating story/memory	3, 127-133
Considering the work-Bridging two worlds/Understanding clients world	making a difference/evaluating therapy/defending work	3, 143-144
Detrimental effect/Groundhog day moment	memory/patching up	3, 146-149
Considering the work-Bridging two worlds/Defend validity-Support world	uncertain outcome/make a difference/evaluating work	4, 155-160
Bridging two worlds/Supporting clients emotional/psychological world	containment-psychological role	4, 163-166
Detrimental effect/Personal impact-Groundhog day moment	difficult/frustration/memory	4, 168-170
Detrimental effect/Personal impact-Groundhog day moment	glaze over/difficulty	4, 173-174
Considering the work-Bridging two worlds/mot & value-making connect	touching/small moments	4, 175-176
Detrimental effect/Personal impact	worry/anxiety tolerate impact	4, 182-188
Considering the work	managing risk/working with others	4, 193
Considering the work / Therapist motivations & values	Reward	5, 203-204
Considering the work	uncertainty/neuroassessment-being detective/diagnosis	5, 205+
Considering the work / Defending validity	what is remembered/in the moment/evaluating work	5, 226-230
Considering the work / Defending validity - ambivalence	therapy limited later stages	5, 242-244
Detrimental effect/Impact dementia	psychological defence/understanding experience	5, 248-251
Considering the work/Defending validity-Understanding client world	diagnosis support/complex/uncertain	6, 260-267
Considering the work/Defending validity	having space to talk/justifying work	6, 275-278
Detrimental effect-bridging two worlds/Impact-Understanding client world	dementia impact on client	6, 281-287
Detrimental effect/Personal Impact	putting self in shoes/existential impact-own mortality	6, 292-294

Considering the work/Diverse approach	extending session length/flexibility/adapting	7, 302-4
Bridging two worlds/Understanding clients world	shift world/effectiveness/evaluating work	7, 306-307
Detrimental effect/Personal impact	young woman fantasy/changing role	7, 313-315
Bridging two worlds/Connecting clients world	past stories / use of therapy	7, 314+
Detrimental effect-bridging two worlds/Impact-Connecting client world	shift/change in relationship role	7, 330-344
Considering the work/Therapist motivations & values	use of supervision/questioning therapy	7, 346-349
Detrimental effect-Bridging two worlds/Impact-Understanding client world	comparing non-dementia - rock the boat	8, 350-361
Considering the work/Therapist motivations & values	drawing therapy to close/supervision	8, 363-364
Detrimental effect/Personal Impact	no happy endings/existential impact/dementia progressive	8, 365-366
Considering the work/Therapist motivation & values	valuing work-success	8, 375-376
Detrimental effect/Personal Impact	what happens to clients/uncertainty/difficult	8, 376-378
Detrimental effect/Personal Impact	relief ending/saved/protected/threat existential	8, 378-379 / 381-386
Detrimental effect/Personal Impact	knowing future-dementia progressive/existential beliefs	8, 388-389
Considering the work/Ambivalence	awareness of limitations/evaluating therapy	8, 391-392
Considering the work/Diverse approach	therapeutic goals/difference	9, 401-402
Detrimental effect/Swimming against the tide	change process different/progressive	9, 409-411
Considering the work/Defending validity	benefit of talking/helping to make sense/justifying therapy	9, 414-416 / 418-421
Considering the work/Defending validity	is this helping?/questioning the work	9, 421-427
Bridging two worlds/Understanding clients world	learning process/clients world/imagination	9, 429-431
Bridging two worlds/Understanding clients world-making connection	Helping into peoples mind/keeping record/educating others	9, 434+
Considering the work-Detrimental effect/Uncertain-Swimming against tide	understanding therapy/measuring change/political/funding	10, 453-459
Considering the work/Uncertainty-ambivalence	exploring unknown-no guidance	10, 466-468
Considering the work-External pressures	current climate- funding	10, 469-470
Considering the work-External pressures	evidence-based work	10, 472-473
Detrimental effect/Swimming against the tide	future uncertainty/challenge/funding	10, 475-479
Considering the work-External pressures	research writing up/gaining understanding/pathway	10, 480-483
Considering the work-External pressures	funding	10, 488-490
Considering the work/Defending validity	hope more services/better assessment	10, 497-498
Bridging two worlds/Understanding clients world	assessment/of dementia/benefits of therapy	10/11, 499-500
Detrimental effect/Swimming against the tide-External pressures	referral process/developing role/fighting stigma	11, 515-519

Detrimental effect/Swimming against the tide-External pressures	funding/not developing	11, 521-522
Detrimental effect/Swimming against the tide-External pressures	Understanding/development potential/ funding issue	11, 524-525

Appendix 12: Cross Case Master Theme Table

Considering the Psychotherapeutic Work

Assuming a Diverse Approach

Brenda: .. the therapy itself was much more intense.. and people sometimes needed shorter times between sessions or sometimes they needed longer time between sessions because they needed more exposure of the of the exercise.. [3, 115-118]

Mmm.. um so it's adapting adapt-adaptation is the name of the game where you start with the behavioural.. approach you might end up with an existential approach or you might end up with a client centred approach. [9, 438-440]

I don't think anybody working with dementing people should only have one therapeutic model they should take the trouble of learning at least two or three so they've got more because if one thing doesn't work you must try something else. [10, 463+]

***Rebecca*:** I might not carry on with therapy in the way I might do with somebody.. er with perhaps without cognitive impairment that um.. so I might need to try adapt things or remember to help them hold on to things. [3, 102-105]

I think the basic approach that.. always stays stays in my mind and is probably most most appropriate with with people with dementia is just I guess a very basic individual formulation so really thinking about what are predisposing factors. [4, 178-179]

So that does fit sort of with often with CBT I guess quite well. So you might be looking for, you know, what's the presenting difficulty, is that being maintained by behaviours or thoughts or feelings and then I guess individual work would be based on that. [4, 190]

So I guess it I probably find it quite helpful to write letters or write sheets with bullet points. [7, 317-318 / 327-328]

***Margaret*:** ..but there's lots of differences there in terms of um how long you'd be seeing someone for so you might only see them for twenty minutes half an hour rather than you know fifty minutes period of time um you'd be working in a much more concrete way um you'd do much more visual um material and pictures and things like that um I think the choice of therapy also is is is is quite.. different. [2, 50-55]

You can do you know a a fairly sort of clear approach using CBT but you might have to give them more written material, make sure they remember things more, structure things much more clearly um do do less in a session um and so on and expect more repetition less generalisation. [2, 57-63]

The other approach which is almost intermediate, which I think fits older people with dementia very well, is using a narrative approach. [] Working with their stories is fascinating and that ties in with older people as well because older people have wonderful stories. [3,112]

..and I said I don't use pure models I mean I think I've illustrated a couple of models but I think often your mixing and matching models quite quite a lot. [4, 191-193]

I used things like flashcards to help her sort of monitoring her thoughts and very thera-thera- therapeutic intervention was one of those squeezy balls so actually when she was having the thoughts the idea was that she squeezed it. [6, 276-279]

I tend to do quite a long tail off I don't see many people weekly at all I tend to see them fortnightly an-and monthly I quite like working monthly with people um but obviously with people with dementia you need to see them more frequently so I you know I I tend to sort of make them the weekly ones if I'm doing the work um but I I like the sort of tailing off quite quite slowly really with people. [11, 510-515]

It's probably adapting the standard ones um I hope you've kind of looked at adapting CBT really that that's fairly straight forward...I tend to find what is therapeutic within the things that are less ob less formal therapy. [11, 535+]

***Sophie*:** The kind of work you might do with people with dementia is really varied as well so a few patients that are suitable for kind of weekly sessions talking things through and the kind of more traditional kind of psychological therapy model but then other people might arrange to do something involving the family or something more indirect or less frequent or there are all sorts of different kinds of work really. [2, 51-56]

So I offered him I don't know kind of ten twelve week contract something like that to talk it through and then we extended it and extended it. [7, 302-4]

***Richard*:** Therapeutically I come very much from a CBT kind of tradition and then I've become terribly eclectic since um and I suppose years ago I would have thought that what they need is a bit of a CBT programme in anxiety management and then things would be okay um I suppose nowadays I'd say what people quite often need is is a little bit of person-centred therapeutic interactions and engagement. [4, 158-163]

There are quite a lot of people who need a much more flexible more therapeutic.. maybe more skilled approach to working with all those kinds of issues. [4, 175-178]

With old fashioned CBT way of doing things then of course people aren't going to do their homework because they're not going to remember what it is that I've asked them to do so it's.. so then you have to think about ways of how you can adapt that and how you can build memory aids into.. into the programme. [5, 213-217]

With people with Alzheimer's disease it it might take longer to get round to it um I would I I do write down a lot more um I quite often work with um postcard size type cards.. um things that people do that you can have in a jacket pocket and things that you can have in a in a handbag sort of thing that.. you know to write down what the tasks are [laughs] um to write down what the reassuring things are that you could remind yourself of um.... so I suppose I suppose that's people earlier on who can who can make use of that. [5, 234-240]

***Julia*:** I've often used um to help people at least have a sense of or continuity of therapy and what they've discussed and how long we've been meeting I'll often use therapy books which are just literally plain notebooks and each session we write down what we talked about and what we're going to talk about at the next session and people find that quite helpful um and lots of sort of written aids and things like that can be quite helpful. [3, 116-121]

It's not a great deal of um alteration that's needed to the therapy really I mean just using sort of notes in sessions and diagrams and things is you know quite enough to help people remember from session to session. [4/5, 199-202]

***Sian*:** What my idea of psycho you know psychological therapy and therapeutic work with people with dementia is is sort of beyond that kind of one to one session um and like I say I I I see walking down the corridor and speaking with someone for ten minutes or five minutes or 30 seconds as a potential therapeutic encounter if you like. [8, 366-370]

***Mary*:** I use a lot of CAT Cognitive Analytic Therapy and because of the life review element I think it fits really well with older adults. [1/2, 50-52]

So yeah it would just depend on on different models used I mean some of the people.. obviously we do some quite behavioural work with people with say moderate dementia or even mild dementia if their mood is a little bit low we might do some very concrete activity scheduling.. rather than more analytic psychodynamic work when you're looking at.. um.... more I guess existential issues or issues about transition or loss.. [6, 279]

***Kerry*:** I'm not saying that with the sort of people that I've seen who have dementia I've done a a full blown CAT therapy I haven't.. but using elements of it to think about the themes of their life and the themes of their relationships.. [4, 172]

Defending the Validity of the Psychotherapeutic Work through Ambivalence and Uncertainty

***Brenda*:** Once that's done I find that people with mild to moderate Alzheimer's Disease can actually work through their their therapeutic goals more or less the same as other people. [14, 654-656]

She had this need to be dependent so I could safely withdraw but it doesn't always happen and um on a personal level that's very often difficult and this is where therapy with demented people is definitely different from with other people young or old. [14, 691-695]

The differences are that you have to be much much more.. aware of the impact on the process and yes the engagement and the disengagement is much longer and is much more complex while the actual working phase is not that not that much different except except in cases of very far advanced work. [15, 741-746]

The main factor that will open up therapeutic options with people with dementia is to treat dementia as any other illness it's no different from the flu or diabetes or MS or anything else.. [18, 876+]

It's not the label that matters it's the process people go through and the help they need with it nobody actually denies a person with dementia the right to use the toilet on time so they should actually have the right to use an outlet for their emotions on time as well and it should be done on time. [18, 885]

***Rebecca*:** Um.. but yeah I suppose then on the other hand there's another issue about whether whether it might be pathologising actually to see people and whether actually linking in people with non-NHS service so the Alzheimer's Society and local day centres where there's sort of maybe not quite so intensive psychological interventions but there's still I guess quite a lot of active listening an-and psychological work whether maybe that is better for people [clears throat]. [3, 143-149]

Um I mean I suppose it is is the cognitive impairment so whether that means.. practically trying to make sure you're sort of understood or things are written down. Um and I suppose it it isn't different in a way because if you're sort of going back to Vygotsky idea I mean you should be working with where people are at anyway. [5, 242-248]

I don't know whether that's all that different when working with old older people in.. I mean I I suppose yeah um maybe it is actually [spoken quietly]. [6, 258-260]

***Margaret*:** ..and they have their high level insight they still have high level of verbal ability and conceptual ability and therefore you can do something quite similar to what you might be doing with someone without cognitive impairment but then you have people where... that they have... limited understanding of their situation their verbal thinking skills are quite limited and there you have to shape the intervention very very carefully to what they can handle. [1, 43-49]

But again it's it's the core approaches as you might do for for someone without dementia. [2, 65]

For some people the engagement in therapy is by seeing you and the more immediate value of coming whereas actually the real therapy is a more sort of profound change um and people with Alzheimer's can actually lose that longer term vision of things. [10, 484-488]

I think it's really the next stage of major research really and.., both getting more sort of case examples, but also you know building a coherent model of how you do it. [11, 548]

***Sophie*:** She did eventually kind of seem to be in a slightly better place and it was partly to do with um a number of other changes going on in her life as well so I couldn't claim it was all to do with the therapy but um there were times when.. especially towards the end she would come in and there was much more of a sense of a kind of coherent person in the room. [4, 155-160]

And it's hard again it it is hard to tell with her how much she she takes in and consciously remembers about what we talk about... but she visibly in the session kind of feels better after talking about things and does she takes in things that I say.. for the time that we're talking.. you know I don't know what she remembers when she goes home but she does find it beneficial. [5, 226-230]

..but the sort of scope for direct talking therapy with them is limited because actually most of the time they just want to go off and carry on with you know their everyday life. [5, 242-244]

For those people having the space to talk about their worries about what's ahead of them.. While they're still able to I think is really really important. [6, 275-278]

There's also.. an awareness of the limits of what you've done and a kind of sadness about that as well I wish I'd been able to do more. [8, 391-392]

As a therapist you would keeping a really careful idea on you know is this therapy actually helping or am I sort of pushing this person to face up to something that is not going to help them to face up to and you know are they working really hard not to face up to it and I'm trying to you know you have to really assess what what you're trying to do all the time, I suppose you do that in therapy anyway but keep questioning to yourself is it helping? [9, 421-427]

***Richard*:** In some ways I think it isn't necessarily different from from other people in that I do think that that at least early stages then the same sorts of approaches apply... that's all things that you would do with anyone. [5, 220-232]

That therapeutic process and relationship and progress does work pretty much in the same way with people with dementia because emotional change works in very much the same way as it works for oth for other people whether people have a conscious memory of that in the end or not. [9, 428-431]

It's kind of giving the theoretical framework if you like for for whatever we're trying to do in a way and then and then it's giving me the kind of it's given us the the language to talk about it in [laughs]. [3, 110-112]

***Julia*:** Working with people with a diagnosis of Alzheimer's is quite.. the Alzheimer's although it it becomes maybe a topic of therapy its effect on therapy is almost quite minimal really. [6, 290-292]

A lot of myths within services that people with dementia can't use therapy that you have to somehow be really um kind of cognitively sound to be able to use therapy um but my experience of working with people with Alzheimer's is that they can really use and benefit from therapy. [4, 194-198]

I think that can sometimes be misinterpreted as um at a psychological level that they're not moving on or they're not able to hear something whereas in fact it's purely that it's taken them a little while to encode it at a verbal level um but after having well with a number of people with you know sometimes quite sort of um severe Alzheimer's I you can see a change through a course of therapy so I think if it if you sort of focusing on just what it was like in those first few sessions and particularly the first few people you work with you'd think it was pointless and it wasn't possible but actually you know after a few years of doing it I can see what a big difference it can really make. [5, 217-227]

***Sian*:** Um and I think that that's quite a big difference um in working with people with dementia...so I think that that's quite a difference um in terms of things like I will hold somebody's hand and I will.. touch somebody on the arm. [5, 228-229 / 244-245]

How psychological therapists and counsellors.. because of their training feel more able to be with someone in their distress and join them in their distress and hear them and listen to them without trying to.. jolly them along or make them feel better or make them feel happy and that actually the process of trying to jolly someone along and make them feel happy can make someone quite.. upset and unheard and not validated and angry. [9, 430-436]

To have the sense of this place that I am in whether it's their own home or somebody else you know that this place that I'm in I have got people that I can talk to I feel safe when I'm upset there's someone who I can speak with who will listen to me. I think counselling fits in with that kind of.. the idea of their view of the world if you like or their view of themselves and others around that this is an okay place for me to be in um rather than this is a scary place where nobody listens to me and nobody you know that a lot the thing that.. the thing that counselling can help with or or psychological work is around just giving someone that sense of safety and that there is people who can listen. [17, 816-824]

***Mary*:** Is it any different? I don't think its therapy therapy I don't think its any different from doing therapy with.. anyone facing any loss of any sort really. [4, 182-183]

I feel really strongly about it now and my my like I said had the group been.. rubbish or had we not seen any changes or.. the one to one work we do with various people with with dementia if we weren't getting the outcomes we measure everything we've got standardised measures everything's outcomed if we weren't getting the outcomes then we would obviously not continue to do it but I think from my point of view our outcomes are really good um and.. yeah I'll keep on doing the work. [5/6, 250-256]

I don't it it it.. doesn't.. differ I I.. just like when people say does working with older adults differ [] ..but just like any....good psychotherapeutic assessment.. you collect as much information as you can in order to inform what treatment you would do and how you'd plan that in the best possible way for the the patient.. so...I don't know how to I don't know what to say about the process.. um....its a therapy process like.. um... any other. [6, 261-272]

The process and the relationship for me is....its its no different really.. um.. I mean it is different but it isn't if that makes sense.. [6, 288-289]

***Kerry*:** I don't know that it feels any different to working with anyone else... I don't.... feel that.... I put a different hat on or that I...... I feel..... any different I think that... um... I think that when your hearing about someone's life.... and your sort of completely available and completely open to their life experience.. you feel.. you feel for them and you sort of feel.. um.. what it must of been like for them... I don't.. I certainly don't look at them.. as tragic because they have Alzheimer's I certainly don't look at their lives as tragic. [3, 108-115]

I think its right to have arguments about whether or not a psychologist needs to do that work whether or not that's work that can be done by.... other health professions who... don't necessarily um cost as much as psychologists and we talk about.. having you know nurse practitioners or social work practitioners um join us in doing this work and potentially we could afford with our resources to pay for more of them and they can afford to pay for chartered clinical psychologists or counselling psychologists.. [4/5, 196-202]

Therapist Motivations and Values

***Brenda*:** That was also the biggest um pleasure that I could actually find. [2,86]

But my reward is when people die in dignity.. er when people don't go to the awful residential home where their where they were destined to go or when people don't get labelled as aggressive anymore just because he hits on account of not being able to talk.. or when people start realising that Mrs What's-her-name um is not being awkward and not being scathing with you.. because she's a nasty woman but because in her world women don't wear trousers… [8, 349+]

***Rebecca*:** I guess just sort of interesting connection to people that had had um.. you know quite er.. you know had had so much life experience but then were I I guess a sense that they were kind of quite sidelined.. um.. by us or you know by our young society really. [2, 64-67]

There's also the Tom Kitwood work about dementia care mapping which I think all his sort of person-centred approach which is really helpful so it makes me really alert to you know what's going on in the environment, who they were as a person, what physical ailments might they have or physical affects of of understanding so I suppose in that way trying to take a more you know er environmental understanding. [5, 202+]

I guess there's the Linda Clare work about cognitive rehabilitation so we've sort of been looking at that trying to go with her own goals to improve her own quality of her life. [5, 230-232]

***Margaret*:** ..but I've worked with older people in in other ways before but and I was very happy to do that in fact I really enjoy it and I'm very very pleased I've done that and er it's very much my specialty of choice. [1, 21-23]

It's a feeling of actually being able to do a good piece of work where you can you know be a proper therapist and allow the emotions to be heard is quite satisfying. [3, 134-136]

***Sophie*:** I like it because it's varied and I guess I like it cause yeah you see people with a whole range of problems across a range of services in a way that perhaps you wouldn't in adult services where the service is much bigger and so you might work in a smaller part of the service. [1, 40-43]

..and it was also quite touching though when when you could say something that would sort of hit the spot and help. [4, 175-176]

…. it's been very.. rewarding to work with. [5, 203-204]

..but you know it has been a valuable piece of work you know you kind of appreciate that. [8, 375-376]

***Richard*:** It's kind of giving the theoretical framework if you like for for whatever we're trying to do in a way and then and then it's giving me the kind of it's given us the the language to talk about it in [laughs]. [3, 110-112]

I've always been I've always felt really quite grateful to her because um she's such a wonderful textbook example of how psychological therapies can work perfectly well for people who are really in relatively advanced perhaps not late stages of Alzheimer's disease but certainly moderate ones and have no conscious memory of having sat with us and talked about anything in particular other than that it was okay and they quite liked you it was alright to talk some more with you um.. so that I always thought that's that's been and it's been hugely motivating. [8, 364-370]

..that's kind of what motivates me and.... and I suppose therapeutic change and success isn't always that impressive and obvious and there's degrees of it and quite often that's that's all we can expect but it's very nice to have some clear cut successful [laughs] examples in the background to kind of keep going. [8, 376-380]

***Julia*:** I think I enjoyed it was because it's got such a mixture of um some really good opportunity for um psychological therapy you can really use a range of different therapies um but also there's quite a strong um neuropsychological element to the job and I particularly liked that work as well. [2, 60-63]

More opportunity for sort of creativity and and I quite like the fact that it's also kind of under funded and a slightly ignored area [laughs] of psychology so it felt like quite a good area to work in really you sort of feel like you can make a lot of difference um sort of promoting the needs of older people. [2, 70-73]

The one area I have worked with people where clients have actually died during the course of therapy and I I think I was really struck once that happened of how important that therapy had been that I felt in such a privileged position that I was the last person to hear their life story and their life story in a lot of detail as well. [5, 229-233]

I suppose it it it's being able to hold in my mind the cases that I have felt have been quite successful that give me that sense of of purpose and that they could have a function. [6, 259-261]

***Sian*:** I was lucky to be exposed to um a person who was a dementia care mapping trainer and so I know quite a lot around person the sort of person-centered the model of dementia and that has been the most influential thing ever in my whole entire life [laughs] basically um and sort of is my main motivating sort of factor there really. [4, 160-164]

I think there's something about working with people with dementia that um.. is has both potential to be highly rewarding and can I get I always think like you know within five seconds you can make a difference.. sometimes and a big big big difference. [8, 359-362]

I don't know there's just something very.. I I don't know it's really weird sort of quite special about.. it's like a privilege or something for people to tell you this.. this almost sort of thing that they just feel a bit ashamed of and to actually share that with you and um.. and like for example people on the dementia care ward will say things like um you know you're you're the first person who or you're I don't know they will just say the most lovely things that you think are just so complimentary like you know 'you're so lovely' and 'you're the only person that I can talk to' and things like this which make you feel quite special. [9, 401-409]

There's something I don't know what it is it's just very.. satisfying very rewarding um and it's not always like that but it's almost like.. yeah it's it's exciting it's um... interesting it's very exciting I think and it's it makes you want to go yay [shouts]. [12, 569-572]

***Mary*:** I find it.. really moving that's why I was really keen to develop.. more groups and do more one to one work with people.. with dementia because I find it a very moving experience. [3, 105-107]

Its painful it's very moving I find it very humbling.. [3, 114]

Being able to initiate psychological plans and implement them and seeing real change.. usually by tweaking something very small um.. that's really rewarding. [3, 130-131]

It was the most.. moving valuable group I I've ever.. we were just amazed at the differences people. [5, 202-203]

..but I'll just keep plugging away at this level and so long as I can feel like I see carers and patients...benefiting from something then....I'll keep going. [8, 378-380]

***Kerry*:** I had some very sort of inspiring teaching from psychologists that were working in older adults during my training and I found that very motivating um and I always had a sense of sort of excitement from them which which I caught.. um and.. I found it very satisfying I found it very fulfilling in the sort of sense of life story [1, 39-43]

So there's that sense of sort of.. really not knowing what well what you'll get next and.. that has been.. um... that has has kept my interest very high. [1, 49-50]

Bridging between Two Worlds

Understanding the Client's World

***Brenda*:** So I have to sort of I have to use much more of my imagination.. to try and find out what's it like for that person?.. [3, 136-138 /148-149]

You must also be very good at your assessment and every sort of three to four, five sessions you must.. go back to the basics and do an assessment where are we? is this still useful?, is this person still benefiting from from therapy?, what are the goals? [5, 229-233]

So we very often used.. parallels like um multiple sclerosis, cancer that kind of stuff diabetes yeah diabetes is a very good model because it can't be cured it can be treated. [6, 259-261]

She actually did say 'I've got holes in my mind.. it's still there but I've got holes in it'...And once she was in a hole you couldn't follow her because I don't have holes in my mind. [10, 452]

***Rebecca*:** Yeah trying to find something a bit about perhaps their temperament as well as um you know any any significant events.. I suppose um yeah things like temperament you know might might an-and how they've reacted to difficulties in their life might sort of give a clue to what the experience of dementia um might be. [4, 181-188]

***Margaret*:** It's partly just spending time talking and validating there own concerns um which inevitably has a life review approach. [2, 75+]

There were sort of themes that came through about losing people and sudden changes and not being in control of things. [6, 256-257]

***Sophie*:** You might see more subtle evidence that something's being taken in and something's being kind of absorbed and held on to but maybe it's not something they can articulate or would even remember. [2, 70+]

After we had talked enough about how she was feeling she would leave hopefully in a little bit more of a settled state. [3, 143-144]

I guess in a piece of therapy like that with someone who didn't have dementia you really would want to try and comment on what was happening and you know people use the therapy for all sorts of things and do escape off into worlds of story telling for various reasons along the way through therapy and the therapists job is to help them see what's happening and to understand what the anxieties are that are making them behave like that and so hopefully then they can move to a better place but with someone with dementia I guess you don't want to rock the boat too much because they are doing it for a reason because the person and the future are terrifying and perhaps having that sort of escape and building a world around themselves where they can feel like they're slightly different and maybe in a slightly different kind of fantasy place isn't a bad thing. [8, 350-361]

It's a learn kind of learning process as well because you're you're hearing about a world that you don't know about um.. you can imagine what it might be like to have dementia but obviously you don't know. [9, 429-431]

I think for some people actually the idea that they might be contributing to your knowledge and helping you into peoples minds I think would be a good thing for them they would like that. [9, 439]

***Richard*:** Rooms now residential accommodation nowadays has got to be single bed and um what they expected her to do [laughs] is settle down in a single room in a place where there were people who were very reminiscent of the staff in a in a institution um and and that's that's what kind of caused all the distress to her. [7, 301+]

I think it probably is important to have an understanding of what it might be like to live with a dementia. [9, 409-411]

***Julia*:** See their difficulties more in light of um.. you know that they have a a a certain tool box to face life with and life just thrown them something that they haven't got the tool for and they just need to learn a new tool to manage that part of their life so they can kind of face it with more of a positive you know hold their self identity. [3, 141-145]

So I think maybe the goals change a little bit if you're working with someone who you know has a diagnosis of a terminal illness I think you often forget that I think we talk about memory problems and we forget that actually it is a terminal diagnosis and I think people's goals for therapy change that it's not about looking to the future or trying to be a different person sometimes it's just a a sense of um kind of reliving their their their life story. [5, 239-245]

It's always struck me how people develop the capacity to live in this world that must continually feel new and frightening um so very often people have still managed to start using therapy and started talking about very difficult issues even though for them it's felt like a first session. [8, 352-355 / 357-361]

***Sian*:** And making making sense I think for me it's about making sense I think that's the thing about working with people with.. all sorts of different cognitive problems but I think particularly with people with dementia is about just trying to under make sense I think that's for me quite rewarding if I've worked out like been a bit of a detective [laughs]. [12, 551-555]

Will also help us as care staff because often people are tearing their hair out because they don't they can't understand and we when we don't understand then peoples empathy just goes out the window so I think for me um.. just anything that helps increase empathy of anybody and understanding I think is a real key to that um.. yeah and that's really satisfying I think. [12, 562-567]

***Mary*:** ..and relationally again its its about facilitating trust like with anyone whether they're psychot they've got psychosis or.. um...mood disturbance its about facilitating a good trusting rapport good engagement.. and where that person can come and feel safe. [6, 272-275]

***Kerry*:** There's a lot happening for them and while they sort of lack full insight into what is happening they have some awareness and then often that awareness shows up as... a a real anxiety or a great deal of fretting about.... the little details of their life. [2, 58-62]

Supporting the Client's Emotional and Psychological World

Brenda: ..and how to recognise where the signs are that is very often the task of therapy.. you know giving people their their control of their life back. [7, 301+]

Rebecca: It's not just the impairment or where they are but that it's still a whole person and how they are adjusting to it.. [2, 87-88]

Margaret: It's nice to feel obviously you're helping someone and you're helping deal with distress because the distress of someone who's got dementia is is not nice and obviously if one can help bring some sort of peace to to what their going through that that helps but the other thing within that um is in a sense to allow people to express their anger. [3, 127+]

And um we did quite a nice bit of work with her a lot of it was actually just allowing her to talk about her self and sort of get a sense of self again and that that often lost in Alzheimer's. [6, 268+]

Sophie: Which over time session after session might hopefully help them feel more settled in them selves having the experience of being kind of held and listened to. [2, 86-87]

For those people having the space to talk about their worries about what's ahead of them.. While they're still able to I think is really really important. [6, 275-278]

The other side of that is that there's the benefit of speaking about the unbearable stuff that that you don't flag anywhere else. [9, 414-416 / 418-421]

Think the therapy there was as much as you know trying to contain something that was essentially falling apart and unmanageable in terms of her whole life really whilst all the other kind of things got into place to make things better. [4, 163-166]

Richard: .. I try to do is is to meet people as peop as people and to try and get just to get a sense if you like for where they are at emotionally and what it might be that they might need from us or from me as part of really um.. to help them engage and to help them to cope and to um.. and to just be generally helpful to them at what's usually a difficult time for them. [3, 119-123]

Is is what what we can do in order to overcome that and what we can do to help people to.. yes to people to overcome that for themselves...I think that's quite a lot of the therapeutic sort of work that would need doing. [10, 494-497]

People need quite a lot of support in order to come to terms with the diagnosis and overcoming the perceptions of stigma and being actually able to then.. you know be much more out there in the way they can organise and prepare their lives for.. a possible per quite lengthy period of deteriorating functioning and health. [11, 504-508]

Julia: You need to be quite sensitive to how you even talk about that and make sure you're you're discussing it in a way that makes sense to the person so for them it's their present your using present tense and not past tense. [8, 389-392]

There are a lot of people who really struggle at both sort of an emotional and family level who could really benefit from some help. [11, 525-528]

Sian: I suppose that's been influenced by a sort of concept that.. um for example Linda Clare has spoken about um that people's awareness of difficulties particularly with you know Alzheimer's disease and similar sorts of dementias that we can often think that a person doesn't have insight when actually it's more a function of the the actual social situation and social psychology and there's a whole load of different issues going on including denial and not feeling safe etc. [7, 300-306]

So I spend quite a lot of time helping a person to feel safe and to feel comfortable and to feel that therapeutic relationship with somebody so that they don't have those sort of maybe psychological barriers that might come in when we start talking about memory problems. [7, 307-310]

How psychological therapists and counsellors.. because of their training feel more able to be with someone in their distress and join them in their distress and hear them and listen to them without trying to.. jolly them along or make them feel better or make them feel happy and that actually the process of trying to jolly someone along and make them feel happy can make someone quite.. upset and unheard and not validated and angry. [9, 430-436]

Just step off of that truth and lies about if someone's Mum is alive or dead and step into the foundation about how a person what's the underlying feeling about are they feeling lonely are they feeling worried um because it's I think very easy to get caught up. [10, 462-464]

Stories that get repeated have meaning and so the things that people keep on saying are they're saying them because there's an emotional reason behind it that keeps coming back into their mind so those things are really important and actually to say to somebody 'look you just told me that' is really missing the point because it's not about that. [11, 517-521]

To have the sense of this place that I am in whether it's their own home or somebody else you know that this place that I'm in I have got people that I can talk to I feel safe when I'm upset there's someone who I can speak with who will listen to me. I think counselling fits in with that kind of.. the idea of their view of the world if you like or their view of themselves and others around that this is an okay place for me to be in um rather than this is a scary place where nobody listens to me and nobody you know that a lot the thing that.. the thing that counselling can help with or or psychological work is around just giving someone that sense of safety and that there is people who can listen. [17, 816-824]

Mary: Someone...coming to terms with the adjustment that they face as a result of the impairment and the impact that that has on their relationships, their independence.. their ability to function. [3, 107-109]

Whilst.. realising that you know the person is still there their emotions remain right up until the end point. [3, 119]

The work very much very often centres around loss and denial.. um acceptance grieving.. and coming to terms with.. with the losses whilst being very um aware of of them.. [4, 179-181]

..but.. like any therapy the the the primary function is for me is to provide a safe containing space within which difficult feelings can be named and explored and held and thought about. [5, 246-248]

You're just holding them in a particular space trying to work with.. where they are right now within the context of...um how they were before.. um but not getting bogged down in.. um or getting completely lost in the despair that they are deteriorating further that there's still.. um....there's still ways to.. work with them to give them what they need. [9, 410-414]

Kerry: There's a lot happening for them and while they sort of lack full insight into what is happening they have some awareness and then often that awareness shows up as... a a real anxiety or a great deal of fretting about.... the little details of their life and um... so.. its challenging work.. [2, 58-62]

They admit, and I can see pretty easily, that they're on much thinner ground when they're talking about the past and this helps their confidence to increase and they can acknowledge that they can say that when we go back.. I sort of know where I am, you know. When we talk about what's happened recently, I feel very lost. [2, 66]

Um I mean I think and we've talked about this recently you know Maslow's hierarchy of needs is very important as an issue but um its great to be able to offer and do psychotherapeutic work and its great for that to have a positive outcome or have the chance of a positive outcome but its... pretty useless if that person isn't having their much more basic needs fulfilled so.. where there are needs relating to housing.. safety.. shelter um... respite of their carers um... you know they are much lower level needs that.. I think.. need to be addressed.. to a.. much improved level than they currently are... [5/6, 246-260]

Making a Connection with the Individual

***Brenda*:** Which model would fit the client best not the client fitting the model the other way round..and that is something I still do I tend to not treat any condition I tend to treat the the person.. [8, 381]

In order to engage you very often must choose another channel than just verbal.. [15, 714+]

Most importantly is to look at peoples humanity to see the person first and the dementia second like you would do with a person with a broken leg like you would do with a person with an amputated leg or a person with a brain tumour. [18, 860+]

The main factor that will open up therapeutic options with people with dementia is to treat dementia as any other illness it's no different from the flu or diabetes or MS or anything else.. [18, 876+]

***Rebecca*:** And then to actually be there with them and sort of see them as a whole person actually interacting with the material and with each other.. um.. so yeah so that was interesting. [3, 123-125]

So I supp I mean that's sort of based on a systemic idea I think [inaudible word] about thickening the plot so rather than the thin story of the person just being really difficult when you try to wash them it's about trying to understand the whole person. [10, 480-483]

***Margaret*:** For some people not all the emotional experience of processing still actually is functioning for some people it's lost quite early on and therefore you're working at quite a different level but for other people despite quite severe dementia and quite poor language um you're actually working at quite an emotional level when you're doing the work with them um and you can see that they are able to process something and you can see that um.. changes happen. [2, 84-87]

I mean probably be diagnosed now would be would be Alzheimer's if you wanted a label. [5, 248-249]

It's called symbolic giving which is quite nice which in a sense is that if if you give something of yourself to a person it can actually um lift the relationship and help it develop so and that can be perfectly true with people with Alzheimer's. [9, 442-445]

Sophie: And it's hard again it it is hard to tell with her how much she she takes in and consciously remembers about what we talk about... but she visibly in the session kind of feels better after talking about things and does she takes in things that I say.. for the time that we're talking.. you know I don't know what she remembers when she goes home but she does find it beneficial. [5, 226-230]

It was a gradual process um.... I think I had the... sort of slow dawning experience that.. [] what he really wants me to do is go oh fascinating what did you do then and you know kind of join him in the story telling and enjoying the stories rather than me trying to think well he's telling me about all his interesting amusing times from his youth but that's because perhaps he's so worried about the present and what's going on and it's a kind of escape but he didn't really want to talk about what that was about um so yeah I think it was the experience of sort of starting to feel like perhaps my therapist contributions are less valued here what he wants is a different relationship with me. [7, 330-344]

Richard: So that even though people might not remember who I am um or what we talked about people can always remember whether they liked me or not. [6, 267-268]

She never did remember who I was in particular she kind of or what I was called or what we were talking about or or any of that but she did remember that it was okay and um that she was okay about talking to me and was quite interested in what that might all be about. [6, 297-301]

I think that an understanding of neuropsychology and the brain is important it's it's und so when we talk about and actually it doesn't matter whether we talk about Alzheimer's disease in particular or whether we talk about dementia the dementias in general because no one Alzheimer's disease is exactly like the next. [9, 435-439]

Julia: So I'll often have people tell me something that's occurred to them or something that they've been thinking about which is actually what we've previously talked about but they've got not recollection of ever talking about it or or when you know when we've talked about it but it seems to have stuck with them they just don't know where it's come from um or I I've had people who from one session to the next don't even remember who I am and yet what we talk about does seem to shift how they feel and they do sort of you can see an emotional shift and emotional change and most of them do start to improve even though they can't remember the therapy sessions. [3, 103-111]

So often people will forget my name and they'll forget where they were going to meet me and what the appointment time and date are but they'll remember what we talk about at sort of an emotional level. [5, 206-208]

I mean it can range really I mean I suppose it's a bit like when working with anyone really that the therapy er the therapeutic relationship can vary so much...I think in the kind of mild milder to moderate stages of Alzheimer's the Alzheimer's plays less of a factor in the therapeutic relationship. [7, 341-342 / 344-345]

I mean I've worked with people that just haven't remembered me from one session to the next it's been very difficult for them to have a sense of continuity or trust or start to feel comfortable in the therapy situation cause every single session has been new to them or has felt new. [8, 348-352]

Sian: So I spend quite a lot of time helping a person to feel safe and to feel comfortable and to feel that therapeutic relationship with somebody so that they don't have those sort of maybe psychological barriers that might come in when we start talking about memory problems. [7, 307-310]

It's better to join someone in their distress than for them to be alone allows me to think well even if this person is crying and upset at least.. I'm they're in a state of attended distress rather than unattended distress and that that's got to be better. [10, 447-451]

I don't actually feel that.. in sort of therapeutic work with people it's so much about what's factually being said it's about.. I see it as looking for.. you know what is this what must this person be feeling if they are saying such and such I think what's that communicate to me about how they're feeling. [11, 501-505]

I really firmly believe that people with dementia although might not be able to remember the content of what's been said they remember on an emotional level what has say for example they remember hopefully I mean this isn't always the case but they will remember that I'm generally an okay person I'm trustworthy, I'm friendly, I'm helpful, I'm I'm okay I'm someone who they can talk to. [14, 658-660]

Um.. so I I definitely have this sense of whilst a person might not be able to remember factually what we have discussed they can definitely remember and hold a therapeutic relate-relationship. [14, 686-688]

I definitely feel it is absolutely possible to make a relationship with someone quite easily with dementia and a therapeutic one and that that can continue even if someone can't remember what has been said. [15, 722-725]

Mary: ..but.. a few people I know challenged the idea why would you work psychotherapeutically with someone with dementia they they.. you know they cant talk so well I think its something like eighty percent.. of our communication even more is non verbal so you don't need to rely on the verbal and if you're doing more psychodynamic work anyway your going to be looking at the relationship and the transference and that doesn't need verbal language. [5, 235-241]

So the diagnosis to me as a psychologist we don't diagnose we formulate. [6, 276]

No as long as you assess accordingly.. and plan.. what you think is best for the person everyone is different so what might suit for one person with.. one type of dementia at a particular level of impairment might not suit another but that's the same.. with any diagnosis so the diagnosis to me is fairly insignificant. [6, 292-295]

Therapeutic relationship is about.. internalising the experience of the therapist so again regardless of whether someone has a.. cognitive memory or an episodic memory.. of what has been said in the therapy that's by the by but as long as they've internalised the experience of the relationship that that will hopefully give them some feelings of security um over time. [9, 438-442]

***Kerry*:** As ever the the sort of the bond between me and them and the sort of sense of trust is.. the most important thing so developing that with them and them coming to see me as sort of a non threatening person who is on their side and who can.. listen and.. hear and receive and reflect back the kind of everything that that their telling me I think is is a good thing I think its its been useful.. [2, 77-82]

I'm aware that things are gonna be more easily forgotten from one session to the next but... that's that's not really a a concern I think the feeling and again the bond isn't forgotten actually I think that that is something that.. is somehow remembered or encouraged because um.... if you've got a good bond people will... sort of... be warm and and trust you week after week. [3, 118-123]

At the very very least what they get from you is a sort of a bond where there's trust and there's respect and there's validation and.. um.. where they listen to you.. [4, 193-195]

I kind of.. without meaning to, sort of covered it then, you know, the therapeutic relationship is the most important thing, you know, as research shows us that, you know, the most important factor is the bond or the relationship regardless of who the therapist is [], the sort of constellation of symptoms that the patient presents with blah blah blah and, you know, the most important thing is the relationship I.. definitely.. believe that so I think, I think it's... something that can be a very, very powerfully positive part.. of therapy. [5, 222]

The Detrimental Effect of Dementia on the Therapist and the Therapeutic Work

Personal Impact

***Brenda*:** Very challenging.. sometimes quite difficult.. it er it can be.. it can have a big impact on on me as a person.. [2, 93-34]

In terms of the actual cognitive damage that the dementia is doing it starts to bite really home for my own.., in terms of impact on my own personal life.. because.. you have to make sure that the client somehow knows that you're the same person [] you can't actually do too much about your hairstyle.., you can't change it too often, if you do have it cut don't cut it too drastically because they might not recognise you. If you have different glasses keep your old ones so that they can remember you. With one lady I even had to make sure that each time I visited her I was wearing the same clothes... which is a big thing because I had to put it in my diary saying wear those clothes.. [4, 170]

..anything with long hair was a woman to this man, anything with short hair was a man, so he went into man to man talk with me which was quite embarrassing.. because sometimes he could be very explicit [laughs] and I learnt a lot about what men are up to when they're just men together[], quite exciting because you can cross the gender gap...where otherwise you wouldn't have that option.. while at the same time.. I want to stay as my own gender, thank you [laughs], and so it's.. it's quite a challenge managing those assaults, unmeant assaults, on your own privacy and on your own feelings. [5, 210]

As I said it can be personally enor-enormously challenging having to make sacrifices with wearing the same clothes.. [7, 316-318]

So and it was quite a surprise when I found myself at the wrong end of a shot gun because nobody had told me about it… and my very first reflex was to put my hands up and get back into my car and get going.. because there's such a thing as protecting my own safety. [9, 401-404]

One of the challenges is to make these little sacrifices that's having to wear the same clothes all the time, having to work dead on time you can't afford to be.. er late you can't afford to stop late.. um sometimes you have to hold on to little rituals such as helping people out of their coat helping people into their coat walking with them to the door so it's very very clear that the interview is over and that they're supposed to go home. [10, 471+]

It's little things that can really eat away on me the biggest personal sacrifice that people make that go into therapy with demented people is that they are going to be very isolated.. because supervisors are very very very difficult to find. [11, 518-526]

You must be flexible enough to make home visits.. but then you have to be savvy enough to ask are there any sons with shot guns or are there any fierce dogs.. [11, 528-529]

I think if I wasn't really made out of plate iron I I think I would have moved out of.. [13, 636-637]

I do become a significant other but who that other is and what significance that has you have to find out because that could be a teacher I could be their substitute daughter.. I could be the girl next door.. I could be their grandson [laughs] I could be their priest.. [16, 757-772]

Yes he wants to kiss me as well yes she drools and she slobbers [makes yuck sound & laughs] it's horrible… slobbers so the best thing to do if she insists on killing you er kissing you is wear a bit of a scarf. [17, 798+]

***Margaret*:** If your trying to come back to the therapist's distress I I what I say to trainees a lot and I still say it to myself as well is that actually the work is inherently quite distressing. [3, 136-138]

Things go wrong with ageing is quite difficult not to sort of not to distance yourself so I think you have to be quite aware of that and um you know I think there's times when it it's quite quite sad. [3, 142-146]

In a sense I was a I was a surrogate man really. [7, 339-340]

***Sophie*:** I you know I do like working with people with dementia it's it's very interesting and challenging um but I couldn't do it as my entire job it has to be a kind of a smallish part of the job. [1, 44-46 / 48-49]

..and that was the kind of effect that she would have on people. [3, 125]
There it was worrying too there you know there was a lot of anxiety in the piece of work and I guess maybe the frustration was partly a response to the anxiety because here is this really worrying situation and this person you're very concerned about.. and you can't physically practically take her and put her in a better place to live where she will be safe um.. and so you have to sort of tolerate that anxiety and I think that can then come out a bit as a frustration as well you know. [4, 182-188]

My God it's terrifying really if I knew that was going to happen to me next year or the year after or.. um... I guess I'd rather be someone without the insight actually. [6, 292-294]

See me in a different light as this kind of young woman that he could sort of escape into this sort of fantasy world really where he could like tell me all these stories from his youth... he wasn't really talking about the present time at all anymore and the reality, you know, that he was an elderly man with dementia and I was his therapist, it was more you know this kind of flirtatious story teller person. [7, 312]

***Richard*:** It's always dangerous to kind of start thinking that someone is typical and therefore we could kind of um jump to conc well there's a danger of jumping to conclusions. [10, 450-452]

***Julia*:** I find it a quite a um sort of humbling I suppose...I suppose I took away from me a sense of actually the little worries in life really don't matter and you know there's really no point focusing on things like that and so I felt I suppose I felt like I learnt something at quite a personal level really sort of makes you realise your own mortality as well. [6, 268-279]

I've had a lot of clients who've written some quite poignant poetry about their experiences of their their partner and spouse becoming their like their child and and their their shifting roles and and also some of the conflicting emotions that the Alzheimer's creates and um in a sense that somebody they loved and really cared for suddenly can become someone that they often don't like anymore or find frustrating or difficult to be around um an I mean and that and that's really sort of a forgotten area I think of the therapy. [7, 322-328]

Um people can also become quite confused about who you are and I've had people shift in the therapy to thinking I'm their daughter or their sister sometimes and that's quite challenging on how to know how to deal with that there's not you know there's lots of literature about kind of boundaries and about time and boundaries outside therapy and what that sort of relationship you should have but obviously if someone's not able to maintain that for neurological reasons and not for psychological reasons and it's distressing to put those boundaries in it's quite difficult sometimes to know how to approach that. [8/9, 392-400]

I mean one particular um man who I can who I did work with who he was he was just very confused in terms of where he was and who everyone was and so and his he wasn't particularly kind of boundaried with his behaviour so he was somebody who would kiss people and cuddle them and and things and obviously if I'm working with someone without a dementia and they started kiss trying to kiss me in the session and cuddle me that would have a very different meaning but it it wasn't him pushing the psychological boundaries or misinterpreting the relationship he would he was just generally very confused in terms of times time and space. [9, 414-421]

***Sian*:** I I kind of see it as every single intervention every single conversation or action or anything at all that I do [laughs] with someone with dementia that I've got in my head that model in my mind so whether I'm just walking from the nursing base to the doctors base where I might be reading some notes I always give myself [laughs] at least ten minutes to make that journey because I might encounter someone with dementia on the way who might be.. in distress or might speak to me and I would feel that it would be very non person centred to ignore that person or to rush by.. [5, 206-213]

..and then also of course it has the potential to be distressing as well um and I think the thing that's more distressing for me is when I see other people not being person centred with people with dementia and I I do find that quite distressing. [8, 363-365]

..and immediately said to me 'don't laugh at me' and I had to obviously stop smiling and um.. and then apologise um but he then probably would have had some recollection known for the future about maybe I was a person who maybe laughed at him. [14, 667-670]

Mary**:** I guess deep down there's a part of me that hopes that if I can work with somebody.. to adjust to that then if it ever happens to me then I might have a bit more insight.. [3, 109-111]

Its painful it's very moving I find it very humbling.. [3, 114]

The dementia as a condition is painful and I do.. experience it in that way but I'm I think I'm accepting of it in as as well as I can do.. but the system around it is what makes it.. really painful because we're constantly fighting a battle.. around trying to get peoples practical needs met and um just them continuing to be valued as a person.. in spite of that they're a person with dementia not a demented person with no other um...values or qualities or or well so that that's the hardest part it's not the condition per say although that's painful it's the it's the response to the condition.. by society. [3/4, 144-152]

Kerry**:** The good thing about a neuropsychological assessment which is assessed their memory and their thinking skills is that it can tell you where their strengths and weaknesses are so that it can tell you and it often does tell you that their attention is very good and their remote memory is good but recent memory and perhaps language isn't so good or recent memory and spatial skills aren't so good.. and your sort of your sort of armed with that knowledge when you go in to psychotherapy with them.. [4, 151-159]

Swimming Against the Tide

Brenda**:** I've had a gentleman that I worked with right at the very end of the process um the work that I was doing was palliative actually just being with him while he was dieing of his dementia.. [4, 196-199]

There was an end to it the end was death.. and that is quite harrowing. [9, 428-434]

There is often.. a lot of frustration at them not getting better. [17, 822-823]

Margaret**:** A big challenge I think is to to to be able to work on what is realistic change for that person because there's lots of things you can't change and you know indeed you know that things will deteriorate um.. so I think the challenge is to find a goal that you can share with the the client that's realistic and achievable. [4, 163-166]

And um she ended up going into hospital and I I think she probably died there in fact she said to me I have this theory I'm going to die when I'm 93 and I would not be surprised if she didn't. [8, 379]

The gains might not be so clear cut you know you could do a good piece of work and then something happen in the persons life and actually it's not totally gone but it's it's dissipated so you have to be realistic about that. [11, 506-509]

***Sophie*:** I'd like to say there was a happy ending but of course there wasn't. [8, 365-366]

But you know at the same time you know what's out there you know what's likely to be happening. [8, 388-389]

But you're very aware that to do that with someone with dementia and partly you're swimming against the tide because you know cognitively they're probably not able to deepen their knowledge of themselves in that way but also that that brings pain and it's a not necessarily going to help them. [9, 409-411]

A lot of political issues.. um in terms of how trusts are funded and organised um I suppose the main thing is it's.. it's not something we know a lot about there isn't a huge evidence base that tells us that therapy with people with dementia is helpful I don't know how you'd measure that change to say show that it was helpful because you can't make people better.. they can't even necessarily fill in a questionnaire that's a where they would say yes it was really helpful for these reasons. [10, 453-459]

Having the luxury of saying well I will see this person I think it could help I'm not quite sure how I'm not sure how long it will take and I [laughs] I'm not sure they'll be able to tell you how it's helped them afterwards you know.. it [sighs] I don't know if that kind of work is going to be funded much in the future in our service or in anyone's services.. [10, 475-479]

I think if enough people are doing it and if people go around writing it up then you know we would start to gather an understanding of how the therapy does work how it can help and what would be the kind of signs that it is helping um.. but that's not really there yet. [10, 480-483]

***Richard*:** There's the whole issue of of the stigma of dementia and people who tend to get it nowadays tend to come from a time when there was a very distinct stigma and it's all very well that nowadays it's much more out there and there's people are much more able to talk about it and things but when you lose your short-term memory and have retrograde amnesia then that's not very much use and for a good while yet probably up to my retirement we're going to mainly see people who do come from a time where what dementia means is um.. is very very stigmatising whatever we do and I suppose that's one of the things to try to work with. [10, 484-492]

People need quite a lot of support in order to come to terms with the diagnosis and overcoming the perceptions of stigma and being actually able to then.. you know be much more out there in the way they can organise and prepare their lives for.. a possible per quite lengthy period of deteriorating functioning and health. [11, 504-508]

Julia: The one area I have worked with people where clients have actually died during the course of therapy and I I think I was really struck once that happened of how important that therapy had been that I felt in such a privileged position that I was the last person to hear their life story and their life story in a lot of detail as well. [5, 229-233]

So I think maybe the goals change a little bit if you're working with someone who you know has a diagnosis of a terminal illness I think you often forget that I think we talk about memory problems and we forget that actually it is a terminal diagnosis and I think people's goals for therapy change that it's not about looking to the future or trying to be a different person sometimes it's just a a sense of um kind of reliving their life story. [5, 239-245]

So I think you know one side is is is really just promoting psychological therapies generally as a treatment of mental health disorders and stressing that a diagnosis of any dementia shouldn't be a kind of contra-indication but then the other side and one that I'm kind of quite involved with now is really promoting the need for more of a psychologically driven memory service. [10, 452-468]

Um I mean I feel like it's a really important area to promote so I think it's really good you know that you're looking at that area and I think particularly in the current climate where there is a risk that older adult services are just going to vanish. [12, 556-559]

Sian: The members of this organisation just couldn't see how it could possibly be relevant to people with dementia because they wouldn't be able to understand because their brains are too what did they say their brains are too... I don't know something very derogatory anyway...Frazzled or tangled up or I don't know their brains are just not capable of of doing counselling. [16, 756-762]

You know this person is responding in this way to this person because they don't actually realise they don't actually understand and if they did understand and that's my job to help them try and understand then they wouldn't be doing this. [18, 867-871]

Mary: I find it a really painful illness.. but I think that personally is more due to the system around it that.. society.. thinks its.. society tries to deny it happens society doesn't really care about it and even though there's all this pushing out with dementia strategy we find at a grass roots level.. um its still very much a hidden illness and people when you say the word dementia people automatically think of someone in the early stages in a nursing home.. incontinent unable to eat.. rather then um recognising that it can be depending on the dementia a slow gradual process.. within which the person um has.. um.. has to go through significant losses um.. potentially and depending on how well they they adjust to those or not. [2/3, 95-104]

I guess because of the nature of it being progressive as well um...you know its going to deteriorate.. um...but again finding kind of realistic hope.. um in terms of yeah again naming and acknowledging that.. [3, 115-118]

I guess the fact that its progressive and you know that from the beginning and that I work with people say from the mild cognitive impairment right through to advanced.. even if its not the same person that I'm seeing across that journey.. being exposed to it I think um definitely doesn't make it easier it makes it harder.. um but makes it because its on the cards its yeah having that awareness rather than denial about it I think.. helps a bit... [9, 414-420]

***Kerry*:** I can certainly see the challenges ahead for them I can certainly see.... how difficult.. things might get not perhaps so much for them but for their families if they sort of live for a long time to come and I can.. you know I'm aware of the sort of... adjustments and losses that they'll all go through. [3, 126-130]

I think the neuropsychological assessment is important as well and I think making that accessible making those results accessible to any therapy.. to any therapist is important you know I guess the nature of dementia is that it progresses and it changes so an assessment that was done six months ago may not may no longer be valid but.. um.. it does help the work to be person centred and it does if if its a relevant and up to date assessment it does help the therapist it does increase the therapists chances of using the persons strengths as much as possible in therapy.. so I think that's another important issue. [6, 260-268]

The therapist always has to be sensitive to the fact that this is a changing.. condition so what they might of thought was possible even a month or six weeks or two months ago may not be possible anymore.. so there is a sense of constantly sort of adjusting perhaps expectations or perhaps goals or just being open to what is.. what is brought um.. and just being open to what can be achieved.. and I think what can always be achieved is a sense of.. respect for.... validating and understanding listening.. um and relating you know I feel that's something that therapists can give. [7, 310-317]

Those Groundhog Day Moments

***Brenda*:** ..this was a lady who could not retain the fact that her husband had died. [12, 577+]

And that is very very moving and it it's also very moving when the penny dropped with that lady who hadn't retained her husbands death once the penny had dropped it was very difficult to see her crying it was very difficult to help her through the moment.. that she was recently bereaved she was bereaved today... but he died two years ago.. so she went instantly from being told that he was dead to the gravestone already being there and having moss on it. [13, 622-627]

Although you can come into very very funny funny business people claiming that they drove in to the interview and they're actually sitting in the wheelchair in pyjamas.. yeah because their memory and the combination of sedative problems are so strong. [15, 710-714]

***Rebecca*:** So I think like another tension or another interesting area is.. um.. um when you would sort of work with someone and be actively listening to them and feeding back ideas to them but that they might not be able to remember between sessions. [2, 94-97]

***Margaret*:** Um and she had she then presented believing that he was still alive and he was visiting her and things were happening and so forth um and it was quite distressing both for her and other people around as well. [2, 91+]

***Sophie*:** What's common about the work I guess is the memory problems...The fact that.. that people don't always [sighs] kind of consciously bring back from one session to the next a kind of recollection of what you've talked about. [2, 65-70]

It was all completely.. surreal in a way she was confused about how this woman had got here the woman was trying to help her and really kind of actively sort of working really hard to make sure this patient got a good service without actually knowing anything about why she was here or what was going on [both laugh]. [3, 116]

It was a bit of a kind of groundhog day [both laugh] experience in that she'd come back again the next week and we'd go through the same thing again and I felt a bit like you know I was patching her up and sending her out there and that she'd just begin to fall apart again when she was on her own. [3, 146-149]

It was difficult, it was frustrating, it was.... It was hard to.. to feel the same level of kind of compassion and empathy.. for a story that you'd heard week after week after week that you knew wasn't true. [4, 168-170]

I mean it was it was hard to stay tuned into how she was feeling and not sort of start to glaze over a bit and say yeah okay I've heard this before. [4, 173-174]

..and also a kind of relief though that you know [sighs] I won't have to hear about it anymore...That in a way you you're going to be saved from something protected from something that was pretty unbearable and relentless and.. yeah those kind of feelings and it comes to sort of helplessness that you're struggling to work with this huge thing that's actually you can't take away or make better um.. so not having to do that anymore and not having to sort of see the.. trying to think what the word is.. grim end is in a way a relief. [8, 378]

***Richard*:** There is this kind of that quite often it feels as if you have to build the relationship again. [9, 417-418]

Because beyond the initial recognition quite often there's no particular recollection [pause six seconds] and I suppose that and that can feel quite repetitive and frustrating. [9, 420-423]

***Julia*:** So I'll often have people tell me something that's occurred to them or something that they've been thinking about which is actually what we've previously talked about but they've got not recollection of ever talking about it or or when you know when we've talked about it but it seems to have stuck with them they just don't know where it's come from um or I I've had people who from one session to the next don't even remember who I am and yet what we talk about does seem to shift how they feel and they do sort of you can see an emotional shift and emotional change and most of them do start to improve even though they can't remember the therapy sessions. [3, 103-111]

It's quite pointless because people will come back and not be able to tell you what they've talked about or often seem really repetitive in the session just going over and over and over the same thing. [5, 214-216]

I mean I've worked with people that just haven't remembered me from one session to the next it's been very difficult for them to have a sense of continuity or trust or start to feel comfortable in the therapy situation cause every single session has been new to them or has felt new. [8, 348-352]

So therapies can often feel quite um sort of almost quite abstract and quite disjointed from reality as as your sort of talking to people about their past but their as far as they're concerned that's their present. [8, 381-384]

***Sian*:** Stories that get repeated have meaning and so the things that people keep on saying are they're saying them because there's an emotional reason behind it that keeps coming back into their mind so those things are really important and actually to say to somebody 'look you just told me that' is really missing the point because it's not about that. [11, 517-521]

***Mary*:** I think there's lots of practicalities in terms of.. getting people to a therapy session given if they've got memory problems.. organising transport can be a problem like its more the practicalities that are issues. [7, 304-307]