

**Self-Discrepancies, Autobiographical Memory and Emotional Distress in Mild
Dementia**

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Abstract

Background: Living with dementia has wide-ranging consequences across both social and psychological domains. Deficits in memory functioning, especially autobiographical memory, and changes in the sense of self have been found to be salient experiences of people with dementia, which may lead to emotional distress. Specifically, discrepancies between how the person sees themselves now (actual self) and who they would ideally like to be (ideal self), or ought to be (ought self) in the absence of the debilitating effects of dementia may be pertinent to levels of emotional distress.

Aims: This study attempted to explore the relationships between self-discrepancies, autobiographical memory, and emotional distress in people with mild dementia.

Method: Thirty-three people living in the community with mild dementia were recruited from Older People's Community Mental Health Teams, charities, and a day care centre. Participants included 23 people with Alzheimer's disease, 4 with vascular dementia, and 6 with mixed dementia, ranging from 64-88 years of age. Participants completed the Selves Questionnaire (measuring self-discrepancies), the Self-defining memory task (measuring autobiographical memory), and the Hospital Anxiety and Depression Scale (measuring emotional distress).

Results: Correlational analyses revealed that greater discrepancies between the actual and ideal selves, and a higher number of reported dementia-related self-attributes were significantly associated with increased emotional distress. A significant relationship was also found between recall of fewer integrative autobiographical memories and higher levels of emotional distress.

Conclusions: The current study provides preliminary evidence of the importance of self-discrepancies and autobiographical memory in understanding emotional distress in people with mild dementia. The way in which people with dementia conceptualise themselves as having a dementia-related self-concept also seems to play a key role in the experience of emotional distress. Further exploration of these relationships would be valuable to help develop future interventions to alleviate emotional distress in people with mild dementia.

1. Chapter One - Introduction

1.1 Chapter Overview

Dementia has been described as the modern epidemic of later life and the most feared diagnosis by older adults (Bond & Corner, 2001). It is a progressive, degenerative disease characterised by cognitive decline and impaired memory, thinking and behaviour (Bates, Boote, & Beverley, 2003). It is also well known for its devastating effects on the sufferer, and as yet there is no cure (Wilson, 2008).

As people in the United Kingdom (UK) are increasingly living longer, the prevalence of dementia is inevitably rising (Alzheimer's Society, 2007). It has therefore become vital to improve our understanding of this debilitating disease in order to minimise distress and improve quality of life (QOL).

The deficits in memory functioning associated with dementia have been well researched, especially impairments in autobiographical memory (AM) (Graham & Hodges, 1997; Greene & Hodges, 1996). These impairments have been linked to both a loss of self in dementia and a reduction in QOL (Jetten, Haslam, Pugliese, Tonks, & Haslam, 2010). However, while the impact of dementia on the sense of self has recently received growing interest in the literature, little is known about how the self, specifically self-discrepancies, relates to emotional distress in people with dementia (hereafter referred to as PWD). Therefore, the present study aims to examine whether there is a relationship between AM, self-discrepancies and emotional distress in PWD.

First, this chapter will describe dementia, the way it is diagnosed, its subtypes, prevalence, and the ways in which it can be managed. Second, the impact of dementia on social and emotional functioning will be discussed, and how these changes may influence the sense of self. Third, the role of the self and identity in

dementia is explored, including an examination of the models of the self that are related to dementia. Self-discrepancy theory (SDT; Higgins, 1987) will be considered here. Fourth, the definition of AM will be outlined, including its functions, a description of the models incorporating AM and the self, and an outline of the AM deficits seen in dementia. The relationship between AM and psychopathology is also discussed. Fifth, a review of the current literature linking AM, the self and emotional distress in dementia will be presented, including a critique of the findings. Finally, the rationale for the current study and study aims will be outlined, along with the research questions and hypotheses to be investigated.

1.2 Dementia

1.2.1 Definition and Diagnosis

The definition of dementia has evolved throughout the years from a non-specific notion of organic brain syndrome to a more precise operationalised concept (Ballard & Bannister, 2005). Historically, dementia has been described with an emphasis on memory loss. However, in more recent decades, the definition has become more inclusive to comprise overall decline in intellectual functioning as well as loss of memory (e.g., American Psychiatric Association; APA, 1987; World Health Organization; WHO, 1992). Dementia is also often described as a condition that is usually chronic and progressive in nature (e.g., Graff, 2009; WHO, 1992). It is distinguishable from the normal cognitive decline that is associated with ageing. Therefore, a diagnosis is only provided where evidence exists that a person's memory and cognitive impairment is higher than would be expected as part of the normal ageing process.

There are numerous sets of criteria used to define and diagnose dementia, including those outlined in the International Classification of Diseases (10th revision)

(ICD-10; WHO, 1993) and the Diagnostic and Statistical Manual of Mental Disorders (4th edition) (DSM-IV; APA, 1994). Criteria can also vary depending on the type of dementia being diagnosed. The different types of dementia will be considered below in section 1.2.2.

Arguably, the most widely used criteria for the definition and diagnosis of dementia are those included in the DSM-IV (APA, 1994). In this manual, dementia is defined as memory impairment and at least one of the following: aphasia (impairment of language ability), apraxia (loss of ability to carry out learned purposeful movements), agnosia (inability to recognise objects, sounds, people, shapes or smells), or disturbances in executive functioning (the ability to think abstractly, as well as plan, organise and manage time and space). These cognitive deficits must also be severe enough to interfere with work, social or relationship functioning. The criteria also suggests that delirium or disturbances of consciousness should be absent when making a diagnosis of dementia.

In addition to the use of the diagnostic criteria in the DSM-IV (APA, 1994), dementia may be screened using semi-structured clinical interviews, such as the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975) or the Addenbrooke's Cognitive Examination Revised (ACE-R; Mioshi, Dawson, Mitchell, Arnold, & Hodges, 2006). Comprehensive history-taking from both the person presenting with difficulties and an informant (usually a relative) is also crucial in the process of diagnosing dementia (Hodges, 2007). Neuropsychological testing may also be employed to provide clinicians with a profile of a person's performance on a variety of tasks, which focus on specific aspects of brain functioning (Blackwell, Dunn, Owen, & Sahakian, 2005). A plethora of other

cognitive screening instruments are available to use but their descriptions are beyond the scope of this thesis (for detailed explanations see Hodges, 1997).

Furthermore, the diagnostic process involves the differential diagnosis of dementia based on subtypes. This can be determined in various ways, including the use of standardised cognitive assessments (as described above), specific neuropsychological profiles, and neuroimaging techniques (e.g., Ballard & Bannister, 2005). Neuroimaging techniques are made up of structural imaging scans (e.g., magnetic resonance imaging [MRI] and computed tomography [CT]), and functional imaging scans (e.g., positron emission tomography [PET], functional magnetic resonance imaging [fMRI], and single photon emission computed tomography [SPECT]). Structural imaging is used to identify the presence and absence of biological features that are specific to certain dementias (Barber & O'Brien, 2005), whereas functional imagery enables the measurement of cerebral function (O'Brien & Barber, 2000). Both can assist in diagnosing dementia, however, Ballard and Bannister (2005) recommend that the diagnosis of dementia and its subtypes is best achieved by combining clinical, neuropsychological, and neuroimaging indices over time.

In the last decade there has been a call for the early detection and diagnosis of dementia (Department of Health; DoH, 2001, 2009; National Institute for Health & Clinical Excellence; NICE, 2007). NICE (2007) state that the early detection of dementia can help PWD and their families by “dispelling anxiety about changes in memory, thinking, mood or behaviour and allowing mobilisation of resources that will be needed in the future” (p. 144). Chang and Silverman (2004) also found that early recognition and active therapy at this early stage can delay the subsequent need

for nursing home care, as well as reduce the risk of misdiagnosis and inappropriate management.

1.2.2 Subtypes of Dementia

There are many different types of dementia, which can be differentiated based on their aetiology. The subtypes of dementia typically fall into one of three categories: cortical (e.g., Alzheimer's disease [AD] and fronto-temporal dementia [FTD]), subcortical (e.g., Huntington's disease and dementia with Lewy bodies [DLB]), or a combination of both (Hodges, 1997).

Some of the more common types of dementia include AD, vascular dementia (VaD), DLB and FTD. Some dementias also occur as a result of the direct physiological effects of a medical condition, such as Creutzfeldt-Jakob disease (CJD) or acquired immune deficiency syndrome (AIDS) encephalopathy. For the purposes of this study, only AD, VaD and mixed dementias were investigated. This is in view of their distinct impairments in AM (see section 1.5.4), which is one of the key variables being examined in the present study. These dementias will therefore be the focus of this chapter.

AD is characterised by loss of memory, especially the memory for learning new information or recalling recent events. As the disease progresses deficits in praxis (e.g., motor activity), language, and executive functioning start to show, as well as behavioural and psychiatric disturbances (also known as behavioural and psychological symptoms of dementia, or BPSD) (NICE, 2007). BPSD may include depression, agitation, disinhibition, apathy, psychosis (hallucinations and delusions), aggression, and changes in eating habits (Howard, Ballard, O'Brien, & Burns, 2001; NICE, 2007).

The onset of AD is often gradual with a progressive decline in cognition and the ability to function. Although there may be brief plateaus in the illness, decline is typically consistent, with a tendency to accelerate or increase over time (NICE, 2007). Neuroimaging suggests that medial temporal lobe atrophy (MTA) is a consistently recognised structural difference in AD as compared to age-matched controls (Barber & O'Brien, 2005). Additionally, Hyman and Trojanowski (1997) have reported senile (neuritic) plaques and neurofibrillary tangles in AD, which indicates that early in the disease the medial temporal regions, including hippocampal formation are most affected (Braak & Braak, 1991). The parahippocampal cortex, and to a lesser degree, the parietal lobes (Ouchi et al., 1998; Stout et al., 1999) have also been found to be affected. It has been suggested that the disconnection of all of these brain regions from associated cortex is responsible for AM loss (Guela, 1998; Hyman, 1984, 1986, 1990). The long-term storage of remote autobiographical memories is independent of the hippocampus (Hou, Miller, & Kramer, 2005), which appears to account for the temporal gradient of AM in AD (i.e., impaired recall of remote autobiographical memories, relative to recent memories) (Graham & Hodges, 1997; Kopelman, 1989).

VaD is typified by mild memory deficits and dysexecutive syndrome (i.e., impairment in goal formulation, initiation, planning, organising, sequencing, and executing) (Jokinen et al., 2006; Mahler & Cummings, 1991). However, the cognitive impairments of VaD can be varied, ranging from symptoms associated with cortical stroke (e.g., difficulties in understanding and problems in expressing thoughts) to those related to subcortical disease (e.g., slowness, forgetfulness and depression) (Kempler, 2005). Clinical patterns of VaD also differ depending on the blood vessels involved in the brain (e.g., large or small), the number, size and

location of infarcts, and the stage of the disease (Jeong, Kim, Seo, & Na, 2009; Kempler, 2005).

The BPSD of VaD usually includes personality changes, depression, emotional lability, inertia, emotional bluntness and psychomotor retardation (i.e., slowing down of thoughts and physical movements) (Erkinjuntti & Gauthier, 2010). Several studies have found that behavioural and emotional changes are more profound in VaD than AD (Aharon-Peretz, Kliot, & Tomer, 2000; Fuh, Wang, & Cummings, 2005), including higher levels of depression and anxiety (Padovani et al., 1995). Neurological symptoms of VaD typically involve gait disorder, imbalance and falls, dysarthria (i.e., problems in articulating speech), dysphagia (i.e., difficulties in swallowing), and urinary incontinence (Pohjasvaara, Mäntylä, Ylikoski, Kaste, & Erkinjuntti, 2003).

VaD is caused by ischemic or hemorrhagic cerebrovascular disease, as well as hypoperfusive ischemic cerebral injury resulting from cardiovascular and circulatory disorders (Román, 2004; Román et al., 1993). It is characterised by a step-wise deterioration (some recovery after worsening) and fluctuating cognitive functions (Erkinjuntti & Hachinski, 1993; Román et al., 1993). The neuropathology of VaD is similar to stroke with infarctions or lacunes concentrated either in the deep grey matter (e.g., basal ganglia and thalamus), or the cerebral white matter (also known as Binswanger disease) (Erkinjuntti et al., 2000). Injury to the basal ganglia may account for subsequent movement and coordination difficulties (Moretti, Torre, & Pizzolato, 2006). Moreover, ischemic lesions are particularly apparent in the prefrontal subcortical circuit, including the prefrontal cortex in VaD (Cummings, 1993). This damage to the frontal lobe is reflected in the dysexecutive syndrome common in VaD (Looi & Sachdev, 1999; McPherson & Cummings, 1996). People

with VaD also show hippocampal neuronal loss (Du et al., 2002; Kril, Patel, Harding, & Halliday, 2002), which is known to predict severity of cognitive impairment (Fein et al., 2000).

Dementia can also have a mixed aetiology, which is primarily made up of AD and VaD (Ballard & Bannister, 2005). Kalaria and Ballard (1999) have reported that at least 40% of PWD have an overlap of vascular and neurodegenerative pathologies. According to Rockwood (2000), mixed AD and VaD can be diagnosed based on a history of focal symptoms (including transient ischemic attacks and strokes), sudden onset, and sudden worsening of otherwise typical AD. Symptoms are believed to follow the same pattern of AD, vascular dementia or a mixture of the two (Alzheimer's Association, 2011).

The differential diagnosis of dementia is based on various types of criteria. For example, the National Institute of Neurological and Communicative Disorders and the Stroke and the Alzheimer's Disease and Related Disorders Association Joint Task Force (NINCDS-ARDA) (McKhann et al., 1984) released criteria for the diagnosis and classification of AD based upon the presence of possible, probable, or definite AD (and the corresponding standards for each of these categories). For the diagnosis of VaD, the longest established criteria were devised by Hachinski et al., (1975) and the Hachinski ischemic score. More recently, the State of California Alzheimer's Disease Diagnostic and Treatment Centres (ADDTC) (Chui et al., 1992) and the National Institute of Neurological Disorders and the Stroke and the Association Internationale pour la Recherche et l'Enseignement en Neurosciences (NINDS AIREN) (Román et al., 1993) have outlined criteria for the diagnosis of VaD.

However, the overlap between AD and VaD can make differential diagnosis difficult. Indeed, autopsy studies revealed that pure AD and pure cases of VaD are uncommon (Hulette et al., 1997; Nolan, Lino, Seligmann, & Blass, 1998). Some studies also suggest that 30-50% of mixed AD and VaD cases are misclassified as VaD (Gold et al., 2002).

1.2.3 Prevalence

A recent report published by the Alzheimer's Society (Dementia UK; Alzheimer's Society, 2007), indicates that there are approximately 750,000 people in the United Kingdom (UK) living with a form of dementia. Of these, 16,000 people are under the age of 65. Prevalence rates from this report suggest that dementia increases with age. For example, dementia is believed to occur in 1 in 1400 people between the ages of 40-64; 1 in 100 people aged between 65-69; 1 in 25 people aged 70-79; and 1 in 6 people aged 80 and above. With people in the UK increasingly living longer it is estimated that by 2021 there will be approximately 940,000 PWD in the UK, which is set to rise to over 1.7 million people by 2051. AD is reported as the most common form of dementia, accounting for 62% of all PWD. This is followed by VaD (17%), mixed dementia (AD and VaD) (10%), DLB (4%), FTD (2%), and Parkinson's dementia (2%). The remaining 3% is made up of other dementias. While AD is currently the most prevalent form of dementia, projections exist that with progressive ageing, VaD will become the most common form of dementia (Román, 2003).

1.2.4 Interventions

Interventions for the management of dementia may target social, psychological, cognitive, or behavioural outcomes. The two main types of

interventions consist of pharmacological and psychosocial approaches, both of which aim to improve these outcomes to some degree.

1.2.4.1 Pharmacological interventions. Several pharmacological interventions for dementia are available and recommended by NICE (2007). These include three acetylcholinesterase inhibitors (AChEIs): rivastigmine (Exelon), donepezil (Aricept), and galantamine (Reminyl). Memantine (Namenda) has also recently been introduced for treating moderate to severe AD (NICE, 2007). It is believed to work by affecting glutamate, a brain chemical involved in memory and learning. AChEIs are used to manage the cholinergic dysfunction that is common in AD (Bowen, Smith, White, & Davison, 1976) and VaD (Court, Perry, & Kalaria, 2002). However, currently no drugs are specifically licensed for the management of VaD, but AChEIs and memantine may be prescribed as part of a clinical trial or at clinical discretion (NICE, 2007). AChEIs work by increasing levels of acetylcholine in the brain (a chemical responsible for memory functioning via the transmission of information between brain cells).

The efficacy of all three AChEIs used to manage AD has been found to be similar (Ritchie, Ames, Clayton, & Lai, 2004). In a review by Birks (2006), which was based on a large number of randomised, double-blind trials, these AChEIs demonstrated modest effects on cognition, activities of daily living (ADL), and global functioning when compared to a placebo. Memantine has also been found to be effective in managing AD (see Tampi & van Dyck, 2007). Some large-scale clinical trials have found donepezil, galantamine, rivastigmine, and memantine to be efficacious in helping with some of the symptoms of VaD (Black et al., 2003; Auchus et al., 2007; Moretti, Torre, Antonella, Cazzato, & Pizzolato, 2008; Orgogozo, Rigaud, Stöfler, Möbius, & Forette, 2002, respectively). However,

evidence presented in the NICE (2007) guidelines suggested that the effectiveness of these drugs in managing VaD is less promising. It was concluded that any possible benefits to people are unlikely to outweigh the potential increased risk of adverse events (e.g., side effects).

Drugs for the alleviation of BPSD include antipsychotics, anxiolytics and sedatives, antidepressants, anticonvulsants, and beta-blockers (see Profenno, Tariot, Loy, & Ismail, 2005).

1.2.4.2 Psychosocial interventions. In view of the interplay between neurological and psychosocial factors associated with dementia (Aminzadeh, Byszewski, Molnar, & Eisener, 2007; Kitwood, 1990), in recent years there has been a shift towards psychosocial interventions to help PWD (see Bates et al., 2004 for a review). The emphasis of these interventions is on improving QOL, which has been deemed as important as medically managing the disease (Grypdonck, 1996, as cited in Steeman, Dierckx de Casterlé, Godderis, & Grypdonck, 2006).

Numerous psychosocial interventions to help with the effects of dementia have been developed, including psychodynamic approaches, reminiscence and life review therapy, support groups, family therapy, cognitive/behavioural approaches, and memory training. However, it is beyond the scope of this chapter to outline all of these approaches (for a review of interventions see Moniz-Cook & Manthorpe, 2009). Given that the present study is focused on the early stages of dementia, only interventions targeted at people with mild to moderate dementia will be discussed.

In reviewing psychosocial approaches for people with mild to moderate dementia, Bates et al. (2004) examined four studies which focused on procedural memory stimulation, reality orientation (RO), and counselling. The former involved training in ADLs, including the use of cues, reinforcement, and prompts to get

people to execute the tasks. RO was developed by Folsom (1968) in order to help reduce confusion in PWD living in institutions. The aim of the intervention is to present orientating information during interactions and the use of props (e.g., clocks, signs, and calendars) to allow for orientation in the person's environment. In Bates et al. review, counselling was described as providing an opportunity for people to express their concerns and receive validated information about their dementia. No evidence was found for the effectiveness of counselling or procedural memory stimulation. However, some findings indicated that RO is effective in improving cognitive ability in AD (Baldelli et al., 1993; Zanetti et al., 1995), with a demonstrable long-term gain at follow-up (Zanetti et al., 1995).

NICE (2007) recommends cognitive stimulation, specifically group cognitive stimulation therapy (CST), to help with cognitive symptoms and general functioning in mild to moderate dementia. This approach is derived from RO (Folsom, 1968) and cognitive stimulation (Breuil et al., 1994). It typically consists of 14 weekly sessions aimed at information processing through themed activities to stimulate and engage PWD, while providing the social benefits of a group setting. CST has been shown to improve cognitive abilities and QOL (Spector et al., 2003) in PWD, and reduce depression (Spector, Orrell, Davies, & Woods, 2001). However, Livingston and Cooper (2010) note that overall there is inconsistent evidence for the utility of CST in helping to improve neuropsychiatric symptoms in dementia.

The NICE (2007) guidelines also advocate the use of cognitive-behavioural therapy for the management of depression and/or anxiety in people in the earlier stages of dementia. In order to improve memory in the early stages of dementia, it is also suggested that life review therapy (i.e., using material from the past, such as

photos, to stimulate memory), and/or a cognitive rehabilitation approach (i.e., memory strategies) be utilised.

Interventions based on aspects of the self in dementia have also showed promising, yet preliminary, results in improving well-being and behavioural outcomes in people in the moderate to severe stages of dementia (Cohen-Mansfield, Parpura-Gill, & Golander, 2006; Romero & Wenz, 2001).

1.2.5 Summary

Dementia is a devastating and progressive disease, which involves significant memory loss and overall decline in intellectual and social functioning. Dementia is becoming increasingly prevalent as the UK population lives longer. The most common types of dementia are AD and VaD, although problems with diagnosis and the overlap between the neuropathology of AD and VaD mean that pure cases of AD and VaD are rarely seen. Diagnosis of dementia is further complicated by the use of numerous sets of criteria. However, the most comprehensive way of diagnosing dementia is via a combination of established criteria, and clinical, neuropsychological, and neuroimaging indices over time. Several pharmacological and psychosocial interventions are available for the management of dementia, which may be targeted towards improving cognitive and social functioning, or the neuropsychiatric symptoms of dementia. The next section will outline the impact of dementia, including the social and emotional consequences for the people with the disease.

1.3 Impact of Dementia

The impact of dementia can be wide-ranging, and has far reaching consequences for PWD, their care-givers, healthcare providers, and the broader society and economy as a whole (Luengo-Fernandez, Leal, & Gray, 2010). In view

of projections that dementia will become the “silent epidemic” of the 21st century (Román, 2003; Royall, 2004), the repercussions for the UK healthcare system and economy are immense. Dementia is thought to cost the UK economy £23 billion per year, which is nearly twice the cost of cancer per year (Luengo-Fernandez et al., 2010). Carers of PWD are one of the most vulnerable groups of carers, suffering from high levels of depression, burden and mental distress, guilt, and other psychological problems (National Audit Office, 2007; NICE, 2007; Schneider, Murray, Banerjee, & Mann, 1999). Indeed, numerous studies have looked at ways to improve psychological well-being and quality of life in carers of PWD (e.g., Charlesworth, 2001; Charlesworth et al., 2008). However, in view of the current study’s aims the next section will specifically focus on the impact of dementia on the people with the disease.

1.3.1 Social Consequences

BPSD are common in dementia, with a lifetime risk of up to 90% (Davis et al., 1997; Marin et al., 1997). These symptoms have all been found to be present in milder forms of dementia (e.g., Moran et al., 2004). Changes in the brain may be accountable for many BPSD (e.g., Cummings & Back, 1998). For instance, the loss of neurons in the locus coeruleus found in depressed people with AD (Forstl et al., 1992; Hoogendijk et al., 1999) may make the person with dementia more susceptible to emotional distress. Moreover, the symptoms in isolation are frequently distressing for PWD (Gilley, Whalen, Wilson, & Bennett, 1991). It has been suggested that certain psychological symptoms, such as depression, serve to exacerbate emotional distress, as well as reduce QOL, and increase cognitive and functional impairment (Banerjee et al., 2006; Greenwald et al., 1989). BPSD are also known to contribute

significantly to economic cost (O'Brien, Shompe, & Caro, 2000), and increased levels of clinical depression in carers (Ballard, Eastwood, Gahir, & Wilcock, 1996).

Impairments in cognitive functioning, ADLs, and behavioural and psychological disturbances have a significant effect on the perceived QOL of PWD (Shin, Carter, Masterman, Fairbanks, & Cummings, 2005). Several studies have found that reduced QOL in PWD has been associated with increased levels of emotional distress for the person (Donaldson, Tarrier, & Burns, 1998; Logsdon, Gibbons, McCurry, & Teri, 2002). Reductions in QOL and subsequent low mood may be further compounded by physical problems associated with older age (e.g., Hopman-Rock, Kraaimaat, & Bijlsma, 1997). Assessing QOL of PWD has therefore become an important area of investigation in order to help target interventions to improve these difficulties (e.g., Hurt et al., 2008).

The presence of BPSD, reduction in ADLs, and subsequent QOL represents excess disability for PWD (e.g., Bleathman & Morton, 1994). This may lead to decreased confidence and consequently a reduction in social contact and environmental stimulation, thereby contributing to lowered well-being (Woods & Britton, 1985). This may be compounded by the "malignant social psychology" described by Kitwood (1997, p.45) (see section 1.4.2.1 for a further description of this model), whereby undermining and discouraging social interactions and care processes lead to a reduction in self-efficacy and therefore further damaging interactions (Sabat, 1994).

These changes and interactions combined may lead to negative effects on PWDs sense of personhood, self-confidence, self-esteem, and the use of maladaptive coping mechanisms (e.g., Bahro, Silber, & Sunderland, 1995; Bamford et al., 2004; Bender & Cheston, 1997). Indeed, consideration of how PWD cope and adjust to the

changes associated with the disease is crucial to providing a psychological understanding of dementia (Cottrell & Schultz, 1993). Numerous studies have explored the coping strategies and phenomenological experiences of people with early-stage dementia (for a review see Steeman et al., 2006). The findings of these studies indicate that PWD go through a process of adaptation (Keady & Nolan, 1995; Pratt & Wilkinson, 2001), whereby they attempt to integrate the disease into their lives by developing strategies to preserve their self-identity (Steeman et al., 2006).

Clare (2000) developed a model of psychological response to the onset of dementia, wherein the impact of cognitive change is experienced in the context of the individual's self-concept and social relationships. She posits that PWD engage in the following five processes: registering the changes; reacting to the changes; trying to explain the changes; experiencing the emotional impact of the changes; and attempting to adjust to the changes. In her study, she found that PWD experience tension between their need to put on a protective layer to maintain their prior self-concept and their need to confront the changes, and allow these to be integrated within their current self-concept. In line with this view, it has been proposed that possible selves (i.e., images of the self in the future) (Markus & Nurius, 1986) are important in understanding changes in the self-concept as a result of life transitions (Hooker & Kaus, 1994).

As this interaction between neurological impairment and social psychology takes its course, the social life of PWD tends to dwindle away (Kitwood, 1990). In turn, it has been suggested by Sabat and Harré (1992) that this may inhibit an individual's sense of social identity, which requires interaction with others in order to be materialised. Indeed, these authors found that personal identity may persist

even into the advanced stage of dementia, whereas social identity may be diminished or even lost over the course of the disease.

1.3.2 Emotional Consequences

Given these vast and devastating changes, it is unsurprising that PWD may experience emotional distress in relation to the discovery that they have, and will need to adapt to, a chronic and irreversible disease. Indeed, as with many chronic and terminal illnesses, the onset of dementia places major demands on coping resources (Cottrell & Lein, 1993). This process of adaptation to dementia involves changes in the sense of self, psychosocial adjustment, and prospects for the future (Frazier, Hooker, Johnson, & Kaus, 2000). The memory impairments associated with dementia may be one cause of emotional distress (a more detailed discussion of the memory deficits in dementia are presented in section 1.5.4). For example, Clare and Wilson (1997, p. 41) summarised the emotional impact memory difficulties can have:

Memory is a very important part of our sense of who we are...It is no surprise that memory problems often have major emotional consequences, including feelings of loss and anger and increased levels of anxiety.

This distress may be further compounded by the social, behavioural, and psychological problems related to dementia, as outlined in section 1.3.1. Some of the responses that PWD have in relation to changes in memory functioning are outlined by Clare (2003), who found that individuals' sense of their self varied in terms of their reaction to memory changes. These ranged from "self-maintaining" (i.e., working to maintain an existing identity), to "self-adjusting" (i.e., developing a new sense of self by incorporating changes into their new identity). In line with this view, Romero and Wenz (2001) argue that when PWD find it too difficult to

integrate new experiences into their prior self-structures, they will react with shame, depression and/or aggression.

PWDs awareness of their difficulties is also related to higher levels of emotional distress, including dysthymia and anxiety (Aalten, Van Valen, Clare, Kenny, & Verhey, 2005). Indeed, people with early-stage dementia are likely to have insight into their illness for a longer period of time and therefore have more time to experience distress (Brierley et al., 2003). This is supported by the findings of Holtzer et al. (2005) whereby the prevalence of depressive symptoms in AD were found to decrease over the course of the disease, with as much as a 30% drop in the fourth and fifth year from baseline to follow up. However, other studies have found no association between the level of cognitive impairment in dementia and depression (Cummings, Miller, Hill, & Neshres, 1987; Haupt, Kurz, & Greifenhagen, 1995).

Estimated rates of depression in dementia range from 30% to 50% (Taylor et al., 2003). In AD, major depression or clinically significant depressive symptoms can be found in between 17% and 40% of people (Holtzer et al., 2005; Wragg & Jeste, 1989). Individuals with subcortical dementia, such as VaD, are more likely to experience depression than those with AD (Sobin & Sackeim, 1997). It has been suggested that a history of depression doubles the risk of developing dementia, particularly AD, due to damage to the hippocampus through excessive glucocorticoid secretion (Jorm, 2001). There is also a general consensus that late-onset depression may be a prodromal feature of dementia (Ritchie, Gilham, Ledesért, Touchon, & Kotzki, 1999; Yaffe et al., 1999), although as noted by Clare (2004), the overlap between dementia and depression is still unclear. Anxiety appears to be less common in dementia, with 12.8% reported in a sample of 704 PWD (Diaz et al., 2005).

1.3.2.1 Self-regulation model of adjustment to illness. Another area that may be relevant to mood and well-being in dementia is the self-regulation model of adjustment to illness (SRM; Leventhal, Nerenz, & Steele, 1984). This model proposes that in order to make sense of their illness, people develop illness representations. These are conceptualisations that people have of their illness based on them noticing their symptoms, gaining information from sources, and comparing these ideas with existing beliefs about health and illness. These illness cognitions fall into five broad areas: illness identity (i.e., the label and perceived symptoms of the illness); beliefs about the cause of the illness; the time line of the illness (i.e., chronic, acute or episodic); ideas about the controllability and curability of the illness; and the perceived consequences of the illness for the person. According to the SRM, illness representations mediate the emotional responses and coping behaviours associated with the illness. Negative illness representations among people with a chronic illness in regard to a strong illness identity and beliefs about serious consequences of their illness have been associated with higher levels of depression and anxiety (e.g., Vaughan, Morrison, & Miller, 2003). Therefore, the SRM may be useful in providing a framework in which to understand individual differences in coping and well-being among PWD (Clare, 2002; Pearce, Clare & Pistrang, 2002).

Clare, Goater, and Woods (2006) tested the SRM in people with early-stage dementia and found that over half of the people they interviewed reported negative emotional consequences as a result of suffering from dementia. These included: frustration, anger, embarrassment, self-blame, feeling useless and depressed, feelings of loss and being cut off, and wishing that one would rather be dead. Self-reported depression and anxiety were higher in people who described a smaller repertoire of

coping strategies. Those people who scored in the clinical range for depression had negative illness representations about the controllability of their illness of dementia (i.e., they believed that either nothing could be done about their diagnosis of dementia or were unable to describe any means of control).

1.3.3 Summary

In summary, the consequences of dementia are wide-ranging. Social problems, adjustment issues, memory deficits, and BPSD all appear to be related to emotional distress in PWD, as well as changes in the sense of self. The next section will consider the relationship between the self and identity and dementia, including a discussion of the models of the self that are related to dementia. SDT (Higgins, 1987) will also be discussed here.

1.4 Self, Identity and Dementia

1.4.1 Self and Identity in Dementia

The self can be viewed as the source of life span experiences, action orientations, and motivational states (Whitbourne, 1985). Identity is considered to be a multidimensional construct (Cohen-Mansfield et al., 2006) and a sub-component of the self, which incorporates a range of self-relevant domains (Fitts, 1965). Barrs (1997) conceptualised identity as a sense of coherence and continuity over time, which provides a unifying context for personal experience. The inherent difficulties in defining the self and identity were highlighted in a recent review by Caddell and Clare (2010), which examined the impact of dementia on self and identity. They highlighted 33 studies which measure the self, or components of the self, in dementia. These studies focused on: social constructionist and interactionist perspectives of the self; embodied selfhood; studies using thematic analyses to

investigate the self and identity; narrative self; self-recognition; self-knowledge; identity based on AM; and the self in relation to role identities.

The overall findings from this review suggest that there is some deterioration in aspects of the self or identity, but that the self is preserved to some degree throughout the course of dementia. However, it is uncertain whether this persistence of self is based on a current or outdated sense of self. It is also still unclear whether individual components of the self are affected independently of each other or if the self as a whole is affected. Moreover, it is not known how the self changes over the course of the disease. Caddell and Clare recommend exploring how the sense of self in dementia relates to other variables in order to inform appropriate interventions for PWD.

1.4.2 Models of the Self in Relation to Dementia

Traditionally, medical approaches have largely been used to understand dementia. These methods have primarily focused on neurological aspects of the disease (e.g., Hyman et al., 1984). However, within the last couple of decades, dementia has been approached in a way that refers to the whole person (e.g., Hart & Semple, 1990). Aminzadeh et al. (2007) argue that neurological deficits alone cannot fully explain the clinical manifestation of dementia, and that psychosocial factors largely influence the experience of dementia.

Indeed, some conceptualisations of dementia emphasise the interaction between neurological impairment and social psychology as a vital factor in determining the level and manifestation of functional disability (Kitwood, 1997; Sabat, 2001). These models stress the personhood of the individual with dementia, and therefore the centrality of identity, self-concept, and emotional experience (Clare, 2002).

1.4.2.1 Personhood model. Kitwood (1990, 1996, 1997) has been influential in developing an alternative paradigm in which to understand dementia. He coined the term ‘personhood’ in relation to dementia to encompass an approach which takes the person into account and not just brain pathology. He proposed a dialectical model of dementia, which reflects the importance of interactions between variables at the biological and psychosocial levels. In his model of personhood, he described the key influence of social factors in how PWD live their lives. He highlighted the importance of retaining intact relationships to enable the person with dementia to experience variety and enjoyment. He suggested a cluster of needs in dementia, which are central to the maintenance of personhood. These include: comfort (providing warmth, tenderness, the soothing of pain and sorrow, and the calming of anxiety); attachment (providing a bond in the face of uncertainties); inclusion (providing a distinct place in the shared life of a group); occupation (being involved in life in a way that is personally significant, and which draws on a person’s strengths and abilities); and identity (knowing who one is, both cognitively and emotionally, and having a sense of continuity with the past – a self-narrative).

In contrast to these enriching interactions, Kitwood (1997) also outlined damaging interactions and processes, which he termed “malignant social psychology” (p. 45). He believed that these “depersonalizing tendencies” (p. 46), may produce a devaluating environment and therefore threaten the well-being of PWD. He described 17 of these tendencies that may be used by people in contact with the person with dementia: treachery, disempowerment, infantilisation, intimidation, labelling, stigmatization, outpacing, invalidation, banishment, objectification, ignoring, imposition, withholding, accusation, disruption, mockery, and disparagement.

1.4.2.2 Symbolic interactionism. Some of Kitwood's (1990, 1996, 1997) model is underpinned by ideas from the symbolic interactionist perspective (Manis & Meltzer, 1967). This perspective focuses upon the ways in which individuals, as active social agents, interpret situations, and shape their social worlds within social contexts (e.g., Hubbard, Cook, Tester, & Downs, 2002). Early in the development of this approach, Mead (1934) elucidated the notion of the self as being based on social constructs, which are rooted in interactions with others. He believed that the self is bound by language and interaction, and therefore can adopt various social roles. He argued that role taking was the key process by which we come to develop a self-concept (i.e., seeing ourselves from the standpoint of others). This is consistent with Cooley's (1902) theory of the looking-glass self, which is based on the tenet that the self is reflected in the reactions of other people, who are the 'looking glass' for oneself (cited in McIntyre, 2006).

Several studies have employed a symbolic interactionist approach to investigate the self in dementia (Fontana & Smith, 1989; Hubbard et al., 2002; Saunders, 1998). The findings of these studies are mixed. Some have showed that the sense of self and identity are retained in PWD, based on the ability to give meaning to non-verbal behaviours (Hubbard et al., 2002), and the capacity to perform identity construction and maintenance in a variety of social interactions (Saunders, 1998). However, another study indicated that PWD lost the ability to interpret other people's actions, and define social situations, which the authors argued is suggestive of a loss of self (Fontana & Smith, 1989).

1.4.2.3 Social constructionism. Similar to symbolic interactionism perspectives, social constructionist approaches posit that language is central to the construction of identity (e.g., Shotter & Gergen, 1989). Based on a social

constructionist model in relation to the self in dementia, Sabat and Collins (1999) have suggested that three types of self exist. Self 1 is considered the self of personal identity, which can be evidenced through the use of personal pronouns (i.e., “I”, “me”, “mine”); Self 2 incorporates one’s beliefs and attributes, as displayed through verbal communication; and Self 3 consists of multiple social personae, which are exhibited during social interactions.

Findings from studies using a social constructionist approach to understand the self in dementia consistently show that all three types of self outlined by Sabat and Collins (1999) persist into the later stages in dementia (e.g., Fazio & Mitchell, 2009; Sabat & Harre, 1992; Sabat & Collins, 1999). However, studies investigating the presence of Self 3 were based on case studies (Sabat, 2002; Sabat & Collins, 1999), therefore the representativeness of these findings are questionable.

1.4.3 Self-Discrepancy Theory (SDT)

One area of the self that has yet to be addressed in the literature on dementia is SDT (Higgins, 1987). SDT is based on the premise that self-inconsistencies produce emotional problems. SDT specifically attempts to distinguish among the different types of emotional problems and how these relate to particular types of self-discrepancies.

SDT contends that individuals have self-guides (i.e., self-directive standards or acquired guides for being), which people are motivated to meet. In SDT, therefore, the self is divided into three components: actual (the self-concept), and ideal and ought selves (self-guides). The actual self refers to the attributes a person believes they actually possess, the ideal self relates to qualities a person would ideally like to have, and the ought self is made up of the attributes a person believes they should possess out of duty. Although individuals may hold both actual and

ought self-guides, Higgins (1987) acknowledged that some people may only possess one.

The theory posits that when discrepancies between the three domains occur, people experience emotional distress. Specifically, Higgins (1987) argued that actual/ideal self-discrepancy (hereafter referred to as AI self-discrepancy) is associated with dejection-related emotions, such as depressive disorders, while actual/ought self-discrepancy (hereafter referred to as AO self-discrepancy) is linked with agitation-related emotions, such as anxiety disorders. Support for these distinctions has been found in several studies (e.g., Higgins, 1987; Strauman, 1990).

1.4.3.1 Self-discrepancies in different populations. Self-discrepancies have been studied in an array of different populations, including undergraduate students (e.g., Bruch, Rivet, & Laurenti, 2000), adolescents (e.g., Papadakis, Prince, Jones, & Strauman, 2006), adults with social phobia and dysthymia (e.g., Weilage & Hope, 1999), adults with a physical illness (e.g., Waters, Keefe, & Strauman, 2004), adults with a TBI (e.g., Cantor et al., 2005), and older adults (e.g., Francis, Boldero, & Newson, 2002; Heidrich & Powwattana, 2004). In Francis et al. (2002) study they found that depression was not predicted by AI self-discrepancies but that current anxiety was predicted by AO self-discrepancies as reported retrospectively for the ages of 20 and 40. Other research (e.g., Heidrich & Powwattana, 2004) showed that higher levels of depression and anxiety were associated with greater self-discrepancies, and poorer physical and mental health was related to AI self-discrepancies.

A review of the evidence applying SDT to the understanding of affective disorders was conducted by Arena (2008). The findings of this review indicate that the proposed links in the theory between the specific self-discrepancies (i.e., AI and

AO self-discrepancies) and corresponding emotional disorders (i.e., depression and anxiety) is contentious and likely to be more diffuse. Indeed, some evidence has been found supporting the association between particular self-discrepancies and specific types of emotional distress (e.g., Scott & O'Hara, 1993; Strauman, 1992). However, it was noted by Arena (2008) that these studies had methodological flaws and were based on undergraduate students in the United States, thereby making generalisability difficult to clinical samples and the UK population. Other studies have found no connection between the specific distinctions of self-discrepancies and particular kinds of emotional distress, but between AI and AO self-discrepancies and negative affect in general (e.g., Ozgul, Heubeck, Ward, & Wilkinson, 2003; Tangney, Niedenthal, Covert, & Barlow, 1998).

1.4.4 Summary

The study of the self in dementia has only received attention in the literature in the past couple of decades. The findings of these studies are disparate, although overall, most have found that the self is preserved throughout the course of the disease to some degree, but that it is also compromised in some way. Several models of the self exist to explain the role of the self in dementia, although one theory of the self that has yet to be explored in relation to dementia is SDT. The next section will outline the definition of AM and its relationship to the self, followed by an exploration of the role of AM in dementia.

1.5 Autobiographical Memory and Dementia

1.5.1 Definition of Autobiographical Memory

AM is defined as a person's life story based on the collected recalled events in their life (Birren & Schroots, 2006). AM is made up of two components – personal episodic memory and personal semantic memory (e.g., Baddeley, 1992;

Dritschel, Williams, Baddeley, & Nimmo-Smith, 1992). The former involves memory for specific personal events (e.g., marriages or births), while the latter consists of personal facts that are not event-based (e.g., names of friends and family, or facts about where one was born).

According to Tulving (1983, 1985), memory can be understood in a hierarchical structure in relation to consciousness (see Figure 1). He proposed that procedural memory is concerned with the way things are done (e.g., skill acquisition), while semantic memory refers to symbolically representable knowledge (e.g., facts about one's life). He further postulated that episodic memory is used to mediate the remembering of personally experienced events. He argued that episodic memory could not function without both semantic memory and procedural memory. He also posited that each of these three memory systems were characterised by a different kind of consciousness – anoetic (implicit, not knowing), noetic (explicit, knowing), and auto-noetic (explicit, self-knowing). He asserted that the essence of episodic memory is based on the combination of three concepts – the self, auto-noetic awareness (self-knowing), and subjectively sensed time (Tulving, 2002). It is auto-noetic consciousness which he believed "...confers the special phenomenal flavour to the remembering of past events" (Tulving, 1985, p. 3).

Similarly, Conway and Pleydell-Pearce (2000) propose that AM is stored hierarchically in terms of different levels of specificity, including general events (e.g., "holidays with X"), or specific events (e.g., "the day I married X"). Given the overlap between AM and episodic memory, the terms will be used interchangeably throughout this thesis.

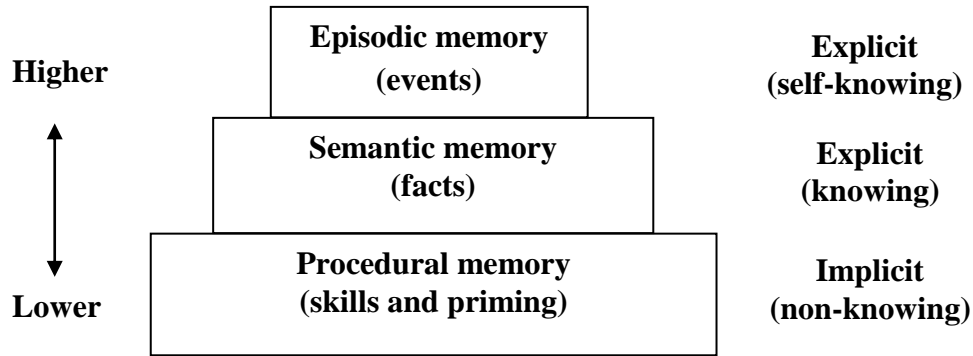


Figure 1. Hierarchical structure of memory according to Tulving (1983, 1985)

Adapted from Shinosaki, Nishikawa, and Takeda (2000)

1.5.2 Functions of Autobiographical Memory

According to Bluck, Alea, Habermas, and Rubin (2005), AM serves three broad functions – directive, self and social. They postulate that the directive function involves using the past to guide present and future thought and behaviour. For example, Baddeley (1987) proposes that AM enables access to old information in order to help solve problems in the present and predict future events. The self function of AM is believed to provide continuity for the sense of self (e.g., Bluck & Levine, 1998), and is particularly important when the self is in adverse conditions that necessitate self-change (Robinson, 1986). Preservation of the self-concept (Wilson & Ross, 2003) is considered as a useful means of self-regulation across adulthood (Cohen, 1998). Finally, it has been proposed that the role of AM enables the development and maintenance of social bonds (e.g., Pillemer, 1998) and the provision of material for conversation needed to facilitate social interactions (Cohen, 1998).

1.5.3 Models of Autobiographical Memory and the Self

1.5.3.1 The reminiscence bump phenomenon. Several researchers have emphasised the link between AM and the self in relation to the reminiscence bump

phenomenon (also known as the lifespan retrieval curve) (e.g., Rathbone, Moulin, & Conway, 2008). The reminiscence bump consists of a period of increased remembering covering the ages of 10 to 30 years of age (e.g., Fitzgerald & Lawrence, 1984; Franklin & Holding, 1977) and is usually observed in people aged about 35 or older (e.g., Rubin, Wetzler, & Nebes, 1986). It has been proposed that identity emerges during late adolescence and early adulthood (Erikson, 1950), therefore potentially leading to self-defining experiences during these life stages (Singer & Salovey, 1993). Some authors have gone on to argue that as events from this period are linked with the formation of the self, this makes them highly accessible (e.g., Conway, 1997; Fitzgerald, 1988) and resistant to disruptions in AM (Conway & Haque, 1999). Associations between the reminiscence bump and the self has been found in numerous studies (e.g., Schrauf & Rubin, 2001; Janssen, Chessa, & Murre, 2007; Cappeliez, 2008).

1.5.3.2 The self memory system (SMS). The importance of AM in relation to the self has further been expanded on by Conway and Pleydell-Pearce (2000), who developed a conceptual framework called the SMS. They posit that the retrieval of specific information about one's personal past is influenced by constructions of the self, including goals, expectations, and self-image. The SMS consists of two parts – the working self and the autobiographical knowledge base. The working self is a complex goal hierarchy, which operates numerous control processes that initiate and monitor goal-directed activity (Williams et al., 2007). The aim of the goal hierarchy is to reduce discrepancies between desired goal states and the current state, thereby regulating behaviour (Conway, 2005). The autobiographical knowledge base is a hierarchical retrieval process, which includes three levels of representation. These include stages of life that occur over a prolonged period of time (lifetime periods),

repeated events that happen over months, weeks, or days (general events) and single or specific events that occur in a given moment in time (event specific knowledge) (Conway & Pleydell-Pearce, 2000).

In this system, it is proposed that a bi-directional relationship between the sense of self and AM exists, in that the goal structure of the working self serves to activate autobiographical remembering and autobiographical memories function to develop, express and maintain the self (Wang & Conway, 2004). Subsequently, autobiographical knowledge grounds the self (Conway & Tacchi, 1996) and allows for the continuity and extension of one's identity over time by enabling the integration of past and present selves (Addis & Tippett, 2004). Indeed, Baddeley (1992) argued that the degree to which previous information about the self, and the extent to which new information is incorporated into a revised sense of self, is likely to be influenced by changes in AM. Conway (2005) further expands on this stating that "...memory and central aspects of the self form a coherent system in which, in the healthy individual, beliefs about, and knowledge of, the self are confirmed and supported by memories of specific experiences" (p.595).

The relationship between the self and memory as proposed by the SMS has been illustrated in several studies (for a review see Conway, Singer, & Tagini, 2004).

1.5.3.3 Narrative identity models. Similarly, McAdams (1996) proposed that identity is a life story – an integration of past, present, and anticipated future. It is believed that for an individual to experience a sense of identity, they must have a coherent life story (i.e., a narrative identity), which is woven together from meaningful autobiographical memories (Sutin & Robins, 2005). Romero and Wenz (2001) further argue that the self is a cognitive schema, which encodes, processes, and maintains information about the person and the environment.

In line with this view, Singer and Blagov (2004) have also highlighted the role of integrative memories in the maintenance of the self. Singer and Blagov (2000-2001) conceptualise integrative memories as narratives in which individuals ascribe meaning to their memories by relating them to lessons about the self, important relationships, or life in general. By virtue, therefore, they are autobiographical memories which have been integrated in the self-system. They further proposed that the meaning-making process in the construction of these self-defining memories enables memory to influence the self (Singer & Blagov, 2004). For example, linked with the SMS (Conway & Pleydell-Pearce, 2000), they argue that linking memories to abstract self-knowledge via meaning making gives extra cognitive, affective and motivational value to memories and therefore powerfully reinforces relevant goals.

1.5.4 Autobiographical Memory Impairments in Dementia

According to Graham, Emery, and Hodges (2004), many cognitive domains are impaired in AD and VaD, including episodic memory, semantic memory, executive/attentional functioning, and visuospatial skills. However, episodic memory is believed to be the most vulnerable in dementia, and is often impaired from the early stages (Shinosaki et al., 2000). Some studies have indicated that AM is more severely impaired in AD compared to VaD (Kertesz & Clydesdale, 1994), while others have found no difference (Almkvist, Bäckman, Basun, & Wahlund, 1993). Numerous studies have found AM to be impaired from the early stages of AD, with more impairment of recent memories, relative to remotely acquired autobiographical memories (e.g., Addis & Tippett, 2004; Graham & Hodges, 1997; Kopelman, 1989). These studies specifically revealed impairments in both personal episodic memory and personal semantic memory. Similar results were shown in a

recent study using a sample of people with VaD, AD and mixed dementias (Naylor & Clare, 2008). MTA found in dementia has also been associated with these AM impairments (Guela, 1998).

It has been argued that a loss of self in dementia occurs through the deterioration of memory and increasing difficulties in communicating (Cohen-Mansfield et al., 2006). This is consistent with several studies which have found that in relation to controls, the greatest impairment in memories of people with AD were from the reminiscence bump timeframe (Fromholt & Larsen, 1991), which as stated above is a crucial period for the formation and maintenance of a stable self (e.g., Conway, 1997; Fitzgerald, 1988).

The impact of cognitive deficits on the sense of self in PWD is well encapsulated in a diary of a dementia sufferer (Cohen & Eisdorfer, 1986, p. 22):

No theory of medicine can explain what is happening to me. Every few months I sense that another piece of me is missing. My life. . .my self. . .are falling apart. I can only think half thoughts now. Someday I may wake up and not think at all, not know who I am. Most people expect to die someday, but whoever expected to lose their self first.

This experience of a disintegrating self may be based on the AM impairments described above. For example, Basting (2003) posits that the self is based on a continuum of memory and creativity that exists in a social context. Therefore, if an individual is suffering from memory loss, she argues that they may suffer a gradual depletion of personal control over their identity, although not necessarily a total loss of self. In view of the proposed link between AM and the sense of self, several studies have focused on AM and the self and identity in dementia (Addis & Tippett, 2004; Naylor & Clare, 2008; Jetten, et al., 2010; Fargeau et al., 2010). All of these

studies, except from Naylor and Clare (2008) found an association between AM deficits and impairments in the self and identity in PWD. These studies will be discussed further in section 1.6.2.

1.5.5 Autobiographical Memory Impairments and Psychopathology

Deficits in AM often include the retrieval of overgeneral memories (OGM) (i.e., categories of events) rather than specific memories. This phenomenon, first identified by Williams and Broadbent (1986) in relation to depression, involves the inability to negotiate the upper levels of the memory hierarchy, which is necessary for the required level of specificity when trying to recall specific events (e.g., episodic memories). This deficit has been found in AD when compared to age-matched, healthy controls (Moses, Culpin, Lowe, & McWilliam, 2004). These findings suggest that people with AD may lack the cognitive ability to engage in an effective and directed search for a specific memory.

OGM has been associated with numerous affective disorders, particularly depression (for a review see Williams et al., 2007). It is therefore hypothesised that PWD will have problems of OGM and thus experience depression.

In light of findings that suggest OGM in dementia (Moses et al., 2004), and the bi-directional relationship between the sense of self and AM (Conway and Pleydell-Pearce, 2000), it is conceivable that PWD who experience this phenomenon may also experience a change in the sense of self. Indeed, recently, Williams et al. (2007) hypothesised that the SMS model (Conway & Pleydell-Pearce, 2000) may account for OGM due to a dysfacilitation of the retrieval process (i.e., a search for a specific event stops prematurely at the general description stage rather than moving on to event-specific knowledge).

Other AM impairments, such as autobiographical fluency (e.g., the ability to describe autobiographical memories) have also been associated with a loss of identity in PWD (e.g., Addis & Tippett, 2004). It may therefore be feasible that deficits in AM and the self, given their adverse impact on PWD (e.g., Cohen & Eisdorfer, 1986), will also lead to emotional distress in this population. In line with this assumption, Jetten et al., (2010) found that AM impairments were associated with a negative impact on well-being, which was mediated by identity loss.

Moreover, it has been proposed that the creation of meaning from memory (i.e., integrative memories [Singer & Blagov, 2000]) assists affect regulation (Robinson, 1986). Blagov and Singer (2004) assert that the ability to learn from experience and to incorporate these life lessons into ongoing self-knowledge is a prime goal in psychotherapy, and therefore argue that the capacity to produce integrative memories is crucial to well-being. They also suggest that meaning making and the construction of integrative self-defining memories are strategies that help people to cope with negative emotions and should be associated with optimal levels of adjustment. Indeed, such a skill has been associated with positive self-regard in college students (Debats, Drost, & Hansen, 1995) and with well-being in parents of disabled children (King, Scollon, Ramsey, & May, 2000). Blagov and Singer (2004) also found a relationship between deficits in integrative memories and adjustment issues in college students. Similarly, Bauer, McAdams, and Pals (2008) propose that “narrative identity provides life with unity, purpose and meaning” (p. 82), which they argue is linked to increased well-being. They assert that growth stories (i.e., personal narratives that incorporate one’s developmental processes) are conducive to well-being. For example, in developmental theories, Rogers (1961)

suggests that when a person is fully functioning they strive to gain a deeper understanding of their inner life.

Blagov and Singer (2004) further argue that attaching a moral or lesson to a memory is a separate cognitive process in addition to general life reflection (e.g., Staudinger, 2001). Therefore, it is conceivable that meaning-making from memories may require more advanced and additional cognitive abilities which, on top of an already deteriorating cognitive system, may be difficult for PWD. As such, it is plausible that impairments in integrative memories will be evident in PWD, given the deficiencies in AM and the self that have been found (e.g., Addis & Tippett, 2004). Furthermore, as deficits in the recall of integrative memories have been linked to adjustment difficulties (Blagov & Singer, 2004), it may be hypothesised that PWD will experience a deficit in the recall of integrative memories and therefore experience emotional distress.

1.5.6 Summary

AM appears to play an important directive, social and self function. Specifically, AM has been shown to play a crucial role in the formation of the self, and vice versa. Deficits in AM, such as OGM and impaired recall of integrative memories have been associated with depression and adjustment problems. AM deficits have been found early in the course of AD and VaD, including OGM, which may lead to depression, as well as produce changes in the sense of self in PWD.

Despite the unique relationship between the self and AM being well-established, these relationships have seemingly yet to be explored in much detail in the literature on PWD. Few studies have also examined the emotional impact of dementia from the perspective of the person with the condition. In the next section, a description of the search strategy used to assess the existing literature examining

the self, AM, emotional distress and dementia is outlined. The existing research will then be discussed and critiqued.

1.6 Search Strategy of Relevant Literature

A systematic review of the literature was undertaken between December 2009 and May 2011 to ascertain what the research findings were linking dementia, AM, components of the self, and emotional distress. Computerised databases, including PsycINFO, MEDLINE, EMBASE, AMED and CINAHL were searched using the terms Alzheimer*, dementia, self, identity, selfhood, personhood, “autobiographic* memor*”, “episodic memor*” and “emotional distress”, distress, anxiety*, depression, depressive*, and dysphoria. Truncation (*) was used where necessary to ensure that different combinations of words were obtained. These terms were all combined and yielded no results. In order to broaden the search, all terms related to emotional distress were then removed and the searches completed again. On this second occasion, 56 studies were found. Abstracts of all articles were assessed for suitability and reference lists of relevant articles were searched to identify any additional appropriate studies.

1.6.1 Inclusion and Exclusion criteria

In order to reduce search bias, articles from all years were searched. Articles were included if they:

- were written in English
- examined a specific aspect of the self, identity, selfhood or personhood
- investigated AM or episodic memory
- used participants who had a diagnosis of AD, VaD or mixed dementia
- were from peer-reviewed journals

Non-empirical studies, book chapters, reviews, dissertation abstracts, erratums and case studies were excluded. In total, four studies met the inclusion criteria (see Table 1). These studies will be examined in the next section of this chapter.

Table 1

Studies Investigating the Relationship between Autobiographical Memory and the Self and Identity in Dementia

Reference	Design	Sample	Measures	Main findings
Fargeau et al. (2010)	Correlational	47 French participants with mild to moderate AD	MMSE (cognitive functioning) AES (apathy) GADS (depression) AM was measured by a scale devised by Piolino (2003) The self was measured by a scale based on the concepts of James (1890) (cited in Fargeau et al., 2010)	<ul style="list-style-type: none"> • 91.5% of participants had impairment in at least one dimension of the self. • 23.1% of participants showed deficits in all three self-dimensions. • Severity of impairment was predicted by deficits in semantic fluency, apathy and age. • Longer duration of illness was related to more impairment in the self. • No significant correlations were found between impairments in the self, depression and episodic fluency.
Naylor & Clare (2008)	Correlational	30 participants with mild dementia ($n = 20$ with AD, $n = 2$ with VaD and $n = 8$ with AD and VaD)	MMSE AMI (semantic and episodic memory) TSCS-II (identity) MARS (awareness of memory functioning)	<ul style="list-style-type: none"> • Lower levels of awareness of memory functioning were associated with poorer AM recall from the mid-life point but with a more positive and definite sense of identity. • No significant relationship was found between impairment in AM and loss of identity.
Addis & Tippett (2004)	Group comparison	20 participants with mild to moderate AD 20 healthy, age-matched controls	MMSE AMI TST (strength, quality and complexity of identity) TSCS-II Autobiographical Fluency Task (Dritschel et al., 1992) (AM fluency)	<ul style="list-style-type: none"> • AD group had significantly poorer identity (strength, quality and direction) than controls. • Deficits in recall of childhood autobiographical incidents were significantly correlated with more abstract responses about identity. • Impairments in childhood and early adulthood personal semantic memory were significantly associated with more definite identity responses. • Deficits in autobiographical fluency for childhood events and early adulthood names were significantly correlated with a weaker identity.

Jetten et al. (2010)	Group comparison	15 participants with mild dementia 16 participants with severe dementia (special dementia care unit) 17 community, age-matched controls	ACE-R (cognitive functioning) AMI QOL-AD (life satisfaction) Personal and social identity was measured by scales devised by Campbell et al. (1996) and Haslam et al. (2008), respectively	<ul style="list-style-type: none"> • AM deficits were significantly correlated with reduced cognitive ability, a loss of personal identity and a reduction in membership of multiple social groups. • AM impairments were significantly associated with less life satisfaction, which was mediated by a loss of personal identity strength but not cognitive ability. • Life satisfaction was significantly poorer for people with mild dementia than community controls.
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Note. AD = Alzheimer’s disease; VaD = vascular dementia; AM = Autobiographical memory; MMSE = Mini Mental State Examination (Folstein et al., 1992); AES = Apathy Evaluation Scale (Marin, Biedrzycki, & Firinciogullarti, 1991); GADS = Goldberg Depression and Anxiety Scale (Goldberg, Bridges, Duncan-Jones, & Grayson, 1988); AMI = Autobiographical Memory Index (Kopelman, Wilson, & Baddeley, 1990); TSCS-II = Tennessee Self-Concept Scale – Second Edition (Fitts & Warren, 1996); MARS = Memory Awareness Rating Scale (Clare, Wilson, Carter, Roth, & Hodges, 2002); TST = Twenty Statements Test (Kuhn & McPartland, 1954); ACE-R = Addenbrooke’s Cognitive Examination – Revised (Mioshi et al., 2006); QOL-AD = The Quality of Life in Alzheimer’s Disease (Logsdon, Gibbons, McCurry, & Terry, 1999).

1.6.2 Examination of the Extant Literature

In line with the SMS (Conway & Playdell-Pearce, 2000), several studies have explored the link between the self, identity and AM in PWD. Addis and Tippett (2004) investigated AM impairment and changes in identity in 20 people with mild to moderate AD and a control group of 20 healthy age-matched controls. They found that the AD group had a significantly poorer identity than controls in terms of strength (fewer identity statements), quality (more abstract and vague responses, and fewer definite identity responses), and direction (lower total identity scores, and thus a less positive identity). Poor quality of identity (i.e., more abstract responses) was also significantly associated with impairments in recall for childhood autobiographical incidents. Additionally, impairments in autobiographical fluency for childhood events and early adulthood names were significantly associated with a weaker identity, indicating that less fluent descriptions when recalling childhood autobiographical events and early adulthood names are detrimental to a strong sense of identity.

These findings are consistent with the reminiscence bump phenomenon (e.g., Rathbone, Moulin, & Conway, 2008), which proposes that autobiographical memories from ages 10-30 are closely linked with identity (e.g., Fitzgerald, 1988). Deficits in the usually highly accessible memories from the “bump” period may therefore weaken the sense of identity in PWD. In line with this view are the findings of Fromholt and colleagues who tested the reminiscence bump in people with AD and revealed that the largest decrease in memories in relation to controls was from the “bump” period (Fromholt & Larsen, 1991; Fromholt, Larsen, & Larsen, 1995).

However, the study by Addis and Tippett (2004) also found that deficits in childhood and early adulthood personal semantic memory were significantly correlated with a higher quality of identity in a different sense (i.e., more definite identity responses). This may suggest that deficits in episodic memory are more damaging than impairments in semantic memory in the maintenance of identity in PWD, although this finding should be treated with caution due to the issues in measuring the self and identity in PWD.

Similar unexpected results were apparent in a study by Naylor and Clare (2008), who examined the relationship between AM, identity and awareness in 30 people with mild AD, VaD and mixed AD and VaD. They found that less awareness of memory functioning was associated with poorer AM recall from the mid-life point, but with a more positive and definite sense of identity. Additionally, they found no significant relationship between AM deficits and loss of identity.

These unforeseen findings and some of those of Addis and Tippett (2004) are inconsistent with the SMS (Conway & Pleydell-Pearce, 2000), in which it is argued that autobiographical remembering is supported by the sense of self and vice versa. However, as already noted, the inherent difficulties in measuring the self and identity, particularly in PWD, where modifications are necessary, may compromise finding the theoretical links proposed in the SMS. Indeed, the identity measures used in the studies by Addis and Tippett (2004) and Naylor and Clare (2008) have not been validated on PWD. Moreover, some participants in Addis and Tippett's (2004) study were recruited from care facilities, which may confound some of the findings, especially in light of evidence that care level may act as an indicator of AM decline (e.g., Jetten et al., 2010).

The findings from Naylor and Clare's (2008) study are interesting as they indicate that identity is preserved even when awareness of memory functioning is limited. They postulate that this may occur for several reasons. First, they argue that the personal database (PDB), which is necessary for the storage of events containing episodes of success and failure on tasks (based on memories in episodic memory) (Morris & Hannesdottir, 2004), may not have been updated. They hypothesise that this may support the belief in PWD that functioning remains at the same level as prior to experiencing dementia. As such, they suggest that individuals will not be primed to integrate changes into their sense of identity and will therefore feel a more definite sense of identity. Second, they propose that PWD may be using psychological defence mechanisms, which are aimed to protect the self from the psychological distress that is linked with failure.

Extending on these studies, several authors have more recently attempted to investigate the relationships between the self and identity, AM, and well-being in PWD. Fargeau et al. (2010) aimed to examine changes in the self in people with AD in relation to behaviour and memory, specifically executive functioning, apathy, depression, and AM. They recruited 47 French participants with mild to moderate AD.

Results showed that 91.5% of participants presented with impairment in at least one dimension of the self, and 23.1% of participants showed impairment in all three self-dimensions. The severity of impairment in the self was found to be predicted by deficits in semantic fluency, apathy and age. A longer duration of illness was also related to greater impairment in the self. However, when exploring the relationships between impairments in the self, depression, and episodic fluency, no significant results were found. These findings indicate partial support for the

SMS (Conway & Pleydell-Pearce, 2000), in that deficits in the self were associated with impairments in semantic fluency, but not episodic fluency. These findings are somewhat contradictory to those of Addis and Tippet (2004) who found that a more definite sense of identity was linked to deficits in semantic memory. Nevertheless, these results are difficult to interpret due to the differences in AM and self and identity measures used across the different studies. Indeed, it is probable that different elements of the self and identity were being measured. The findings of Fargeau et al. (2010) also imply that mood is not a key factor in relation to the self and AM in PWD.

However, the findings of this study should be treated with caution due to several methodological limitations. First, the authors use an unstandardised scale to measure AM (Piolino, 2003) and do not describe how participants' answers were recorded or coded, making it difficult to replicate the findings. Second, there is no report of whether these answers were coded by independent raters, therefore researcher bias cannot be ruled out. Third, using caregivers responses to measure impairments in the self is problematic as it does not take the experience of the person with dementia into account, and thus lacks ecological validity. Fourth, the study was conducted with French participants, making it difficult to generalise the results to a UK population of PWD.

Jetten et al. (2010) also recently explored the impact of AM deficits and identity loss on the well-being in people with mild to severe dementia and age-matched controls. They found that AM loss was significantly associated with reduced cognitive ability and with a loss of personal identity strength and a reduction in membership of multiple social groups. Impaired AM was also significantly associated with less life satisfaction, which was mediated by a loss of personal

identity strength but not cognitive ability. Life satisfaction was significantly poorer for people with mild dementia than community controls.

Unlike the findings of Fargeau et al. (2010), the results of this study suggest that loss of identity is not only a negative consequence of AM deficits but is also critical in predicting well-being in PWD. This is consistent with narrative identity models (e.g., Singer & Blagov, 2004; Bauer et al., 2008), which propose that identity and the meaning that this provides for individuals in their lives is important for well-being. The findings also lend support to the SMS (Conway and Pleydell-Pearce, 2000), in that deterioration in AM corresponded with loss of identity. Nevertheless, although the results of this study are interesting, the findings should be treated with caution. For example, the reliability and validity of some measures used in this study are questionable as non-standardised measures were used to assess identity and limited psychometric data was reported for these scales. Moreover, the type of dementia is not documented, which limits the ability to draw comparisons with other studies.

1.6.3 Critique of the Evidence

This section includes a discussion of the overall findings of the studies, and an evaluation of the methodological issues in relation to the measures used, data collection, and participants used.

1.6.3.1 Overall findings. The findings of the four studies are mixed, which may in part be attributable to the different aspects of self and identity that were being investigated, as well as the small sample sizes used. All studies found that some deficits in AM were associated with impairments in some aspects of the self and identity, with the exception of Naylor and Clare (2008), who found the opposite (i.e., poorer AM was related to a more positive and definite sense of identity). Similarly,

Addis and Tippett (2004) also revealed that deficits in childhood and early adulthood personal semantic memory were significantly correlated with more definite identity responses, although they also found that some deficits in AM were related to a weaker identity. Jetten et al. (2010) found that impairments in AM were significantly associated with less life satisfaction, which was mediated by a loss of personal identity strength. These results suggest that loss of identity not only has a negative effect on memory but is also critical in its effects on QOL. However, Fargeau et al. (2010) found no significant results between the self and depression scores, indicating that in their sample depression was not a factor in the impairment of the self and AM.

1.6.3.2 Methodological issues. The findings in the current literature examining the self or identity and AM must be considered in light of the methodological flaws evident in most studies. For example, one difficulty apparent in assessing the findings of the studies is the different ways in which the self or identity were measured. In two studies (Addis & Tippett, 2004; Naylor & Clare, 2008), the TCSC-II was used to measure identity strength, direction, and quality. This measure has good psychometric properties; however, it is a measure of self-concept, and not specifically a measure of identity. Given that the two studies which employed the TCSC-II only used some parts of the TSCS-II to score identity, it is possible that the content validity of the measure was compromised. Moreover, the TCSC-II is not validated for use in dementia populations. It was also noted by certain authors (Naylor & Clare, 2008) that some participants found the task too demanding. Several studies also used non-standardised measures of self and identity (Fargeau et al., 2010; Jetten et al., 2010), or adapted measures (Addis & Tippett,

2004), therefore making it difficult to determine the reliability and validity of the measures, as well as presenting a challenge to the comparability of findings.

Overall, AM was measured using the AMI, except for the studies by Fargeau et al. (2010), who used a scale by Piolino (2003), and Addis and Tippett (2004), who employed the Autobiographical Fluency task (Dritschel et al., 1992) in addition to the AMI. No psychometric properties were reported for either of these measures, therefore reliability and validity cannot be determined. The AMI is an appropriate and standardised measure to study AM, and has been widely used and validated. However, it is recognised that the AMI does not assess the period between early adulthood and recent life (Graham & Hodges, 1997), which may be important when investigating participants who are in the older age range (Naylor & Clare, 2008). The latter authors attempted to rectify this in their study by adding a section in for mid-life, however, they concede that this is a non-standardised part of the measure, and therefore firm conclusions about their findings in relation to this section cannot be drawn. It has also been acknowledged that when assessing AM in relation to the self, the AMI may not tap into the types of memories central to the formation and maintenance of the self (Caddell & Clare, 2010). Several studies also did not report the coding process for some of the measures they used (Fargeau et al., 2010; Jetten et al., 2010), or whether independent raters were used to code a proportion of the responses given. This means that inter-rater reliability cannot be established for these measures, and therefore researcher bias cannot be discounted.

Overall, the studies in this review used relatively small sample sizes and are therefore susceptible to Type I and II errors. Furthermore, small numbers of participants can limit firm conclusions being drawn from the data gathered, and therefore reduce external validity. The only study that reported a power analysis in

relation to the sample size required was Naylor and Clare (2008), who, despite a small sample size of 30, reported that they had sufficient power to detect significant effects.

The reporting of demographic variables for the samples was fairly poor across the four studies. No studies documented the ethnicity of participants, and only two (Addis & Tippett, 2004; Fargeau et al., 2010) reported the education level of participants, which is problematic when attempting to compare studies. The latter two studies were also conducted outside of the UK, making it difficult to generalise the findings to a UK population. Nevertheless, a strength of the Fargeau et al. (2010) study was that it measured illness duration, enabling a correlation between this and the self to be made. One study (Jetten et al., 2010) did not report the range of scores on the ACE-R, and another (Fargeau et al., 2010) failed to document a mean score on the MMSE. These flaws present a challenge when trying to compare the results from the studies and cause difficulty in determining the generalisability of the findings.

Another difficulty evident in comparing the results between studies is based on the variety of groups of PWD that were recruited. For example, one study did not report the type of dementia diagnosed and recruited people from care homes in the mild to severe stages of dementia (Jetten et al., 2010). Fargeau et al. (2010) also recruited people in the mild to severe stages from a Neurology Department, but only used participants with AD, although they did not state if participants were living in the community or care homes. Addis and Tippett (2004) only used participants with AD, but their sample was made up of people in the mild to moderate stages of dementia and some were recruited from care homes and others from the community.

Only Naylor and Clare (2008) recruited people in the milder stages of dementia from the community, although they used people with AD, VaD, and mixed dementia.

1.6.4 Summary

The overall findings of the review suggest that the association between the self or identity and AM is equivocal. This may, in part, be due to the methodological flaws apparent in the literature. Indeed, the quality of the current literature is confounded by a lack of consistency in the measurement of the self or identity and AM. This is further exacerbated by the use of unstandardised or adapted measures. The studies were also based on a variety of concepts in relation to the self or identity. While this may be a strength of the current literature as it considers the self or identity from various standpoints, it also limits any firm conclusions from being drawn about the nature of the self or identity in dementia, and is also problematic for comparing findings. The use of relatively small sample sizes also limits the extent to which these findings can be generalised to the wider population of PWD, while the use of heterogeneous groups of participants in several studies makes delineation of findings difficult. The next section will outline the rationale for the study, along with the aims of the current study. Research questions and hypotheses for the present study are also presented.

1.7 Rationale for the Study

The results of this literature review indicate that, to date, no studies have explored self-discrepancies and emotional distress in PWD. One study has examined the relationship between components of the self, AM and depression (Fargeau et al., 2010), although this study had methodological flaws, was conducted outside of the UK, and did not measure the self from the perspective of the person with dementia. Additionally, while Jetten et al. (2010) investigated the relationships between life

satisfaction, identity and AM in PWD, they did not specifically measure emotional distress.

In line with Higgins' (1987) SDT, it is hypothesised that both AI and AO self-discrepancies will occur in individuals with dementia resulting in emotional distress for the following reasons. First, in view of the relationship between AM and the self (e.g., Conway & Pleydell-Pearce, 2000), and given that AM is impaired in AD and vascular dementia (e.g., Graham & Hodges, 1997), it is argued that the sense of self will be altered in dementia, resulting in self-discrepancy between the actual-ideal and actual-ought selves. Moreover, in view of the role of AM in developing, expressing and maintaining the self (e.g., Bluck et al., 2005), deficits in AM are likely to challenge and alter the sense of self.

Second, the changes and impairments that PWD experience in respect of their functioning, as well as receiving and adjusting to a diagnosis of dementia, are likely to affect aspects of their self and identity as shown in the existing literature outlined above. This may therefore cause conflict for PWD between their actual self and who they would ideally like to be, and who they feel they should be in the absence of the debilitating effects of dementia. This is in line with the findings of Clare (2000), which showed that PWD experience tension between their prior and current self-concept. Additionally, in view of the relationship between certain illness representations (e.g., a strong illness identity and beliefs about uncontrollability of one's illness) and emotional distress (e.g., Vaughan et al., 2003; Clare et al., 2006), and the negative emotional consequences described by PWD about their disease (e.g., Cohen & Eisdorfer, 1986; Clare et al., 2006), it is plausible that PWD may define their current self-concept in terms of the effects of dementia, and therefore experience emotional distress.

The association between memory deficits, specifically AM impairments (e.g., OGM and deficiencies in the recall of integrative memories) and emotional distress/adjustment difficulties have also all been linked (e.g., Moses et al., 2004; Singer & Blagov, 2004b). Thus, in view of the AM impairments already found in dementia (e.g., Graham & Hodges, 1997) and their association with a loss of self and identity (e.g., Addis & Tippett, 2004), it is conceivable that deficits in AM will not only be associated with changes in the self, but also result in emotional distress for PWD.

Most studies exploring the relationship between AM and the self in dementia have typically measured AM using the AMI, which it has been recognised may not tap into the types of memories that are fundamental in the formation or preservation of the self (Caddell & Clare, 2010), or memories from the mid-life point (Naylor & Clare, 2008). The current study therefore attempts to address this by using the Self-defining memory task (SDMT; Singer & Moffitt, 1991-1992), which is specifically designed to measure memories of experiences that reflect a person's identity and how they define themselves.

Indeed, Singer and Salovey (1993) describe self-defining memories as recollections that are emotionally intense, repetitive, vivid, and comprise enduring concerns about oneself. These memories represent recollections of experiences that reflect one's identity because, by definition, self-defining memories comprise narratives that individuals draw on to inform their sense of identity (Blagov & Singer, 2004). Singer and Salovey also found that eliciting self-defining memories resulted in a higher proportion of memories deemed important to the participant than a standard autobiographical memory task. This may therefore be a beneficial

approach to understanding AM in dementia given that the self is assumed to be closely linked to AM.

1.7.1 Study Aims

The majority of the evidence provided above indicates that the sense of self is affected in dementia to some degree, whether as a result of cognitive deficits, or via the adverse behavioural, psychological and social consequences of the dementing illness. Nevertheless, how the self is altered and to what extent still remains unclear. Similarly, there appears to be a large amount of research, which suggest that emotional distress is commonly experienced in PWD as a result of these factors. The current study therefore aims to delineate some of these factors by first examining if self-discrepancies are related to emotional distress in people with mild dementia. Second, it will explore whether certain impairments in AM (e.g., OGM and fewer integrative memories) are associated with emotional distress in PWD. Third, it aims to investigate if self-discrepancies are associated with AM deficits. Fourth, it attempts to investigate if PWD define their current self-concept in terms of their dementing illness, and if this is associated with emotional distress. In examining these areas, it is hoped that the current study will expand on the existing literature investigating the self and AM in dementia, as well as provide a novel examination of how these variables relate to emotional distress in PWD.

1.8 Research Questions and Hypotheses

Based on the review of the existing literature, the primary and secondary (exploratory) research questions and hypotheses to be explored in the current study are outlined below.

1.8.1 Primary Research Questions

1. Is there a relationship between self-discrepancies and emotional distress in people with mild dementia?
 - Primary hypothesis 1: Greater self-discrepancies (as indicated by AI and AO self-discrepancies) will be related to higher levels of overall emotional distress.
 - Secondary hypothesis 1: Higher AI self-discrepancies will be associated with higher levels of depression.
 - Secondary hypothesis 2: Higher AO self-discrepancies will be associated with higher levels of anxiety.
2. Is there a relationship between OGM and depression in people with mild dementia?
 - Primary hypothesis 2: Recall of fewer specific memories will be associated with higher levels of depression.
3. Is there a relationship between AM integration and emotional distress in people with mild dementia?
 - Primary hypothesis 3: Recall of fewer AM integrative memories will be associated with higher levels of overall emotional distress.

1.8.2. Secondary Research Questions

1. Is there a relationship between self-discrepancies and AM in people with mild dementia?
 - Secondary hypothesis 3: Greater self-discrepancies (as indicated by AI and AO self-discrepancies) will be associated with recall of fewer specific memories.

- Secondary hypothesis 4: Greater self-discrepancies (as indicated by AI and AO self-discrepancies) will be associated with lower levels of AM fluency.
 - Secondary hypothesis 5: Greater self-discrepancies (as indicated by AI and AO self-discrepancies) will be associated with recall of fewer integrative memories.
 - Secondary hypothesis 6: Greater self-discrepancies (as indicated by AI and AO self-discrepancies) will be associated with recall of fewer AM memories from the childhood and early adulthood lifetime periods.
2. Is there a relationship between dementia-related self-attributes and emotional distress in people with mild dementia?
- Secondary hypothesis 7: Greater dementia-related self-attributes will be associated with higher levels of overall emotional distress.

2. Chapter Two - Method

2.1 Chapter Overview

This chapter will outline the design of the present study and details about the participants recruited. Inclusion and exclusion criteria will be described, along with a discussion of the ethical considerations regarding recruitment. The measures used in the study will then be outlined, followed by a description of the procedure used in current study. The chapter is concluded with a section detailing the planned analyses.

2.2 Design

This study employed a correlational design to investigate the relationship between AM, self-discrepancies and emotional distress. Measures of these three respective areas were given to participants at a single time point. In the next section, the sample used in the current study will be described and an outline of how they were recruited is provided. A power analysis is also described, along with the inclusion and exclusion criteria. Ethical considerations in relation to the sample are also discussed.

2.3 Participants

A total of 33 participants completed the questionnaire booklets, 22 of whom were male, and 11 of whom were female. The ages of participants ranged from 64 to 88 years old, with a mean age of 77.61 years ($SD = 5.76$). The length of time since being diagnosed with dementia ranged from one month to 66 months ($M = 16.44$, $SD = 15.75$). Participants were recruited from the Norfolk region in the UK from Older People's Community Mental Health Teams (OPCMHTs), charity groups and a day care centre (Table 2).

An invitation letter or email (Appendix A) was sent to team leaders and managers of these locations to inform them of the study and request permission to attend a team meeting to highlight the study to staff, or to ask to attend a carers or cared for group/meeting. A participant information sheet (Appendix B), a poster advertisement for the study (Appendix C), and the inclusion and exclusion criteria were also included. A request to advertise for potential participants via the poster was also made, where this was appropriate. Following consent from team leaders and managers, the lead researcher visited the different teams and groups/meetings to outline the details of the study to staff members, and/or carers or the cared for. Staff were asked to approach any potential participants to take part in the research who they felt may be interested and appropriate, in light of the inclusion and exclusion criteria. Similarly, carers were also asked to discuss the research with their relative if they were suitable to see if they would like to take part. It was requested that they give any suitable individuals a participant information sheet and to ask them if they would give consent to provide their contact details (Appendix D) for the lead researcher to call them if they did not contact the lead researcher directly themselves. Where permission was given to advertise, posters were placed on service noticeboards to publicise the study. The posters were headed with the slogan 'Research into the psychological understanding of emotional distress in mild dementia.' Brief details of the nature of the research were outlined, along with the lead researcher's name and contact details.

Table 2

Source of Participants

Type of Service	Number of Participants Recruited (%)
OPCMHT	24 (72.7)
Charity group	8 (24.2)
Day care centre	1 (3.0)

Note. n = 33

2.3.3 Power Analysis

A power analysis completed prior to the study commencing indicated that the number of participants required for the study for an acceptable level of statistical power (.80) to complete a correlation was 21. This was assessed using G*Power (Faul, Erdfelder, Lang & Buchner, 2007). The parameters for this analysis were based on a large effect size ($r = .5$), and alpha at .05. A large effect size was used based on previous research which found a large effect size for PWDAM deficits and impairment of identity in AD ($r = .56$) (Addis & Tippett, 2004).

2.3.4 Inclusion and Exclusion Criteria

Participants were included in the study if they:

- 1) were aged 18 and over
- 2) had a formal diagnosis of probable AD, vascular or mixed dementia (this was established by speaking to a member of staff or a carer)
- 3) were in the early-stages of dementia, as indicated by an MMSE (Folstein et al., 1975) score of 18 or above

Participants were excluded from the study if they:

- 1) lacked mental capacity to consent to taking part in the research
- 2) had any other form of dementia
- 3) had insufficient fluency in English

- 4) had any acquired language problems, preventing ability to communicate adequately
- 5) had any other neurological abnormalities other than those associated with their dementia

Criterion number three of the inclusion criteria was set based on other studies in the area that have used people in the earlier stages of dementia (e.g., Naylor & Clare, 2008). Criterion number two of the exclusion criteria was included because AM impairments are typically only salient in AD and vascular dementia (e.g., Almkvist et al., 1993; Graham & Hodges, 1997), therefore only these types of dementia and mixed dementia were explored in the current study. Additionally, the latter three exclusion criteria were set to enable the use of standardised self-report measures and are similar to the exclusion criteria used in other studies in this area of research (e.g., Addis & Tippett, 2004; Naylor & Clare, 2008).

2.3.5 Ethical Considerations

Ethical approval to conduct this study was sought from Norfolk Research Ethics Committee (National Health Service) and a favourable opinion was granted (Appendix E). In addition, Research and Development approval was applied for to Norfolk and Waveney Mental Health NHS Foundation Trust, Suffolk Mental Health Partnership NHS Trust and Cambridgeshire and Peterborough NHS Foundation Trust. Approval was provided by all three. However, no participants were recruited from the latter two Trusts as a sufficient number of participants were obtained from Norfolk.

2.3.5.1 Informed consent. Before participants took part in the study, they were required to read a participant information sheet, outlining details of the study and their rights to withdraw at any stage without it affecting current treatment they

may be receiving. Once they had read and understood the participant information sheet, and indicated that they were willing to participate, they were asked to initial and sign a consent form, to show their willingness to take part in the study. At least 72 hours were given between participants receiving the participant information sheet and signing the consent form. No coercion or deception was used in this study and participants' decision to take part was entirely voluntary.

2.3.5.2 Confidentiality and anonymity. Questionnaires were provided in an anonymised booklet, which was coded and only accessible to the lead researcher and her supervisor. Codes were not used on consent forms so there was no way of identifying a participant's responses. If participants wished to be informed about the findings of the study, they were given the opportunity to leave their contact details on a separate sheet. These details were kept separate from participants' questionnaire booklets. Contact details were destroyed after feedback was provided. Participant information was stored securely and only accessible to the lead researcher and her supervisor. Paper information was stored in locked cabinets and electronic information was kept on a computer and/or data stick requiring a private password, which only the lead researcher and her supervisor had access to. This information included no personally identifiable data. All data was used in accordance with the Data Protection Act (1998) and will be destroyed after 15 years.

2.3.5.3 Risks to the participant. Possible risks to participants were minimised in several ways: 1) participants were advised on the participant information sheet to contact their General Practitioner (GP) or healthcare/key worker if they had any concerns or felt distressed as a result of taking part in the study, 2) following completion of the questionnaire booklet, a debrief was given by the lead researcher (a trainee clinical psychologist), and participants were given the

opportunity to raise any concerns or ask any questions, 3) participants' GP and/or healthcare/key worker were informed of their patient's involvement in the research, and 4) participants were provided with the contact details of the NHS Patient and Advice Liaison Service (PALS), and the supervisor of the lead researcher at UEA (a clinical psychologist) on the participant information sheet if they wanted to discuss any concerns they had about the study.

2.3.5.4 Mental capacity. In order to ensure that participants had mental capacity to consent to participate in the study, the following action was taken: 1) discussion with a participant's healthcare/key worker to establish their professional opinion of the person's mental capacity to consent to participate, and 2) when participants were given the participant information sheet to read the staff member who provided the sheet and/or the lead researcher made an assessment of whether the person was able to give meaningful consent to participate. This was assessed by the participant's understanding and willingness to be involved. It was also checked whether they could retain the information provided to them and weigh this up in order to make, and communicate, a decision. These actions are in accordance with guidelines set out in the Mental Capacity Act (1983).

In the next section, the demographic information of the current sample is outlined. The measures used in the present study are also described.

2.4 Measures

2.4.1 Demographic Information

A questionnaire was given to participants requesting a range of demographic information (Appendix F). Details of these demographics are presented in Table 3. In addition, participants were also asked about care and living arrangements, and the

type of services that they were currently using. This information is summarised in Table 4.

Table 3

Demographic Information for Participants

	Frequency	Percentage
Marital status		
Married	27	81.8
Divorced	1	3.0
Widowed	4	12.1
Cohabiting	1	3.0
Ethnicity		
White British	33	100
Education level		
Some secondary	22	66.7
GCSE or O-Level	5	15.2
A-Level	3	9.1
Diploma	1	3.0
Undergraduate/Postgraduate	2	6.1
Employment		
None	32	97.0
Voluntary	1	3.0
Type of dementia		
AD	23	69.7
VaD	4	12.1
Mixed dementia	6	18.2
Previous mental illness		
Depression	3	9.1
Post-traumatic stress disorder	2	6.1
Bi-polar disorder	1	3.0
Dementia medication		
Donepezil	17	51.5
Rivastigmine	5	15.2
Galantamine	4	12.1
Involvement in other interventions		
CST group	9	27.3

Note. n = 33

Table 4

Participant Living and Care Arrangements and Service Use

	Frequency	Percentage
Living arrangements		
Home	33	100
Type of carer		
No carer	2	6.1
Family carer	26	78.7
Friend and paid carer	1	3.0
Family and paid carer	3	9.0
Paid carer	1	3.0
Number of carers		
0	2	6.0
1	23	69.6
2	5	15.1
3	3	9.0
Services used		
OPCMHT	26	78.7
Charity	3	9.0
Day care centre	3	9.0
Memory club	1	3.0

Note. $n = 33$

2.4.2 Mini-Mental State Examination (MMSE; Folstein et al., 1975)

The MMSE was used to assess level of cognitive impairment in the current study. It is a brief assessment of global cognitive impairment in dementia, which is scored out of 30. Scores of 24 or under indicate a dementia syndrome. Typically, mild dementia is suggested by a score of 18-24 and moderate to severe dementia by scores of 17 or less (Folstein et al., 1975). The MMSE has good levels of internal consistency (Cronbach's alpha = .90) (Albert & Cohen, 1992) and test-retest reliability ($r > .75$) (Tombaugh & McIntyre, 1992). Construct validity has also been found to be adequate (Jones & Gallo, 2000) as well as concurrent validity with the

Wechsler Adult Intelligence Scale (Wechsler, 1955) ($r = .66$) (Folstein et al., 1975). Other tests of cognitive impairment, such as the ACE-R (Mioshi et al., 2006) were considered for use, however, the MMSE was deemed most appropriate for use in the current study as it is widely used in research (Jones & Gallo, 2000), and is also a very brief measure, therefore placing less burden on participants.

2.4.3 Selves Questionnaire (SQ; Higgins, Klein, & Strauman, 1985)

The SQ (Appendix G) was selected to assess self-discrepancies in the present study. This is an idiographic free recall measure, which assesses individuals' current discrepancies between their self-representations of their 'actual' (the type of person they believe they currently are), 'ideal' (the type of person they hope or aspire to be) and 'ought' selves (the type of person they believe it is their duty to be).

Respondents were asked to verbally provide the lead researcher with up to 10 attributes for each of these self-states. They then rated the extent to which they felt they possessed that attribute on a scale ranging from 1 (*slightly*) to 4 (*extremely*).

Self-discrepancies were calculated in a standardised format according to the method described by Higgins, Klein, and Strauman (1987). The AI and AO self-discrepancies were determined by comparing each 'actual' self attribute to the attributes listed in the 'ideal' and 'ought' self lists using an online thesaurus tool (www.thesaurus.com). Specifically, each word pair was classified as either: 1) a synonymous match (if the words were synonyms and differed by less than two extent ratings) (weighted by -1), 2) a synonymous mismatch (if the words were synonyms and differed by two or more extent ratings) (weighted by +1), 3) an antonymous mismatch (opposites) (weighted by 2), or 4) a non-match (if the words were neither synonymous or antonymous) (weighted by 0).

Based on Higgins et al. (1987) scoring system, these weighted frequencies were then summed to provide a measure of self-discrepancy magnitude. Scores are calculated on a continuous scale, with a score of 0 or below signifying self-consistency and a score above 0 representing self-inconsistency (self-discrepancy). These scores were used in the analyses of the current study. Additionally, actual self-attributes were coded for whether they appeared to be dementia-related (e.g., confused, forgetful). Scores ranged from 0-10 and the total score was used in the analyses of the present study to assess dementia-related self-attributes. An independent rater blind to the research questions and hypotheses coded 20% of responses for AI and AO self-discrepancies, and the number of dementia-related self-attributes. Inter-rater reliability was found to be acceptable (see section 3.4.2). Where there was disagreement on coding, discussion took place until agreement was reached.

The SQ has been used with older adults and effectively identified AO self-discrepancies (e.g., Francis, Boldero, & Newson, 2002), thereby indicating that it was appropriate for use in the current study. The reliability and validity of the measure is also acceptable. Inter-rater reliabilities between .80 and .94 have been found (e.g., Scott & O'Hara, 1993; Strauman & Glenberg, 1994) and test-retest reliabilities range from .39 to .65 over 4 weeks to 2 months (Moretti & Higgins, 1990). Content validity has been established to some degree as discrepancy scores have been found to be associated with emotions in the manner that self-discrepancy theory predicts (i.e., AO self-discrepancies are associated with depressive disorders, while AO self-discrepancies are related to anxiety disorders) (e.g., Strauman & Higgins, 1987). However, the discriminant validity of the SQ between AI and AO self-discrepancies has been questioned due to high inter-correlations between the two

constructs (e.g., Tangney et al., 1998). Nonetheless, the SQ is still widely used in self-discrepancy research (see Arena, 2008).

2.4.4 Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983)

The HADS was used to measure emotional distress in the current study. It is a quick, 14-item self-report measure used to assess levels of anxiety and depression independently over the past week. Unlike some other measures of depression and anxiety, it excludes somatic symptoms, therefore avoiding potential confounding issues (Snaith & Zigmond, 1994). It is routinely used in older people research (e.g., Flint & Rifat, 2002) due to the co-existence of physical health problems being more likely in older age. Therefore it was considered appropriate for this study. Given that self-discrepancies are correlated with depressive and anxiety symptoms (e.g., Strauman & Higgins, 1987) it was important to measure both anxiety and depression in the current study. This measure therefore enabled the measurement of both of these constructs, and an overall emotional distress score, whilst also making testing less onerous for participants.

Each question has four possible responses which are scored on a scale from 3 to 0. The maximum score is 21 for depression and 21 for anxiety. A score of 11 or higher indicates the probable presence of a mood disorder and a score of 8-10 is suggestive of a disorder (Zigmond & Snaith, 1983). Each sub-scale on the HADS is divided into four ranges: normal (0-7), mild (8-10), moderate (11-15) and severe (16-21). Although originally tested on people aged 16-65, the HADS has been found to be an effective bi-dimensional measure of depression and anxiety in older adults, with high internal reliability (Cronbach's alpha = .77 and .76 for the depression and anxiety sub-scales, respectively) and construct validity (Flint & Rifat, 2002). A separate score for anxiety and depression was used in the analyses of the current

study. Additionally, an overall emotional distress score was calculated and used in the analyses by summing the scores on the anxiety and depression sub-scales. This can be utilised a global distress measure (Bjelland, Dahl, Haug, & Neckelmann, 2002).

2.4.5 Self-defining memory task (SDMT; Singer & Moffitt, 1991-1992)

The SDMT (Appendix H) was selected to measure AM in the present study. This task requires individuals to identify five self-defining memories, broadly described as “a memory from your life that you remembered very clearly and that still feels important to you even as you think about it” (Singer & Moffitt, 1991-1992). Participants were required to articulate their memories to the primary researcher, and responses were recorded verbatim. Participants were then asked to rate how they felt about recalling the first memory out of the five they retrieved in terms of the emotions that they felt, and also how vivid and important the memory was to them. This was done using a scale of 0 (*‘not at all’*) to 6 (*‘extremely’*). They also indicated how many years ago the memory took place.

For this study, coding was carried out in accordance with Singer and Blagov’s (2000-2001) manual, which stipulates that memories can be coded by their structure (specific or general) and meaning (integrative or non-integrative). A specific memory was defined as being a unique occurrence with a duration of less than one day (e.g., “the day that I got married to my wife...we were dressed up to the nines and it was a beautiful day”). An integrative memory was defined in terms of what the memory had taught the individual and how it had conveyed meaning in their life (e.g., “the death of my mother was a turning point in my life and I came to realise that life is too short not to do what you want”). A score for AM specificity was based on the total number of specific self-defining memories given (0-5).

Similarly, AM integration was scored by the total number of integrative self-defining memories reported (0-5). In the analyses of the present study, the specificity score was used to measure OGM (i.e., a lower score indicated OGM) and the integration score was used to assess AM integration (i.e., a lower score indicated impairment in AM integration). Inter-rater reliability for these categories has been found to be within acceptable limits (.54-.98 for structure and .70-.72 for meaning) (Singer & Blagov, 2000-2001).

In the current study, self-defining memories were also assessed for which life stage the memory was retrieved from. These consisted of childhood (before the age of 18) and early adulthood (ages 18-30). The scores for each lifetime period ranged from 0-5 memories and total scores for each lifetime period were used in the analyses of the current study to assess AM lifetime period. Timeframes were included in the present study in view of findings which suggest that memories from certain life periods have been closely associated with the self and identity (Fitzgerald, 1988; Conway, 1997). Lifetime periods have previously been assessed in self-defining memories (e.g., Sutherland & Bryant, 2005). The level of fluency of memories is also typically used to assess AM (e.g., Ditschel et al., 1992). Therefore, this was measured in the current study by summing the number of words used to describe five self-defining memories, providing a total AM fluency score, which was used in the analyses.

In view of the present study's aims to explore the self and AM, this measure was chosen because it specifically indexes memories that are personally important to the individual, rather than valenced memories which are typically accessed in autobiographical memory cueing tasks (Jansari & Parkin, 1996; Rybash & Monaghan, 1999). Given that valenced memories are less relevant to the research

aims than memories that are self-defining, the SDMT was considered the most appropriate measure for this study. Indeed, Singer and Salovey (1993) found that eliciting self-defining memories resulted in a higher proportion of memories deemed important to the participant than a standard autobiographical memory task. In this study, a proportion of memories (20%) were coded for specificity and integration by an independent rater blind to the research questions or hypotheses. Acceptable levels of inter-rater reliability were achieved (see section 3.4.2). Where any disagreement was apparent in coding, discussion took place until agreement was obtained.

In the next section, the procedure used in the current study is outlined.

2.5 Procedure

Participants who were recruited via an OPCMHT were initially approached by a member of staff within the team. The member of staff provided a participant information sheet to the individual. Participants were asked to read this sheet. After reading the information sheet, if individuals showed an interest in participating in the study they were asked to sign a form with their contact details indicating their consent for the lead researcher to contact them. In the case of participants recruited through charity groups or the day care centre, either potential participants or their carers were approached by the lead researcher. Following this, the same procedure outlined above was carried out.

During initial contact the staff member or lead researcher made an assessment to see if the participant had mental capacity to consent to participate in the research. Only participants deemed to have mental capacity were provided with an information sheet and asked to take part. Where participants were identified via a discussion with their carer (a relative), the inclusion and exclusion criteria were

outlined to the carer. Then together with a member of staff a judgement was made whether a participant may be suitable for the study, and whether they had mental capacity to consent to participate in the research. Where a judgement was made that a participant lacked, or may lack, mental capacity to consent to the research, they were not asked to take part in the study.

Participants who were deemed to have mental capacity to consent to the research were provided with two options to indicate their willingness to take part. For example, they were informed that they could either contact the lead researcher directly if they wished to take part using the contact details of the researcher that were provided on the participant information sheet. Or, if they had given consent to use their contact details, the person was informed that they would be contacted by the lead researcher after a week to see if they wished to participate in the study.

Once participants had provisionally agreed to participate (either via directly contacting the lead researcher themselves or by providing their written consent to be contacted by the lead researcher), a brief telephone conversation took place with them and usually a carer to see if they still wished to take part. For people who declined to take part, their contact information was destroyed and no further contact was made. If agreement was given to participate, it was first checked to see if participants had read the participant information sheet and understood the details of the study. During this time, the lead researcher made an assessment of the person's mental capacity to take part in the research. It was also checked to see if they met the inclusion criteria. Participants were given the opportunity to ask any questions about the study. If participants chose to proceed to participate, a convenient time and location was agreed upon for the person to complete the questionnaire booklet

with the lead researcher. All participants wished to be seen at home; therefore all assessments were completed in participants' homes.

The questionnaire booklets included the demographic information, the SQ, SDMT, MMSE and HADS. Two different sets of booklets were used to counterbalance the measures, in order to control for order effects. These consisted of the demographics, SQ, SDMT, MMSE and HADS (booklet A) and the demographics, SDMT, SQ, MMSE and HADS (booklet B). The MMSE was given after the assessments used to measure AM and self-discrepancies to avoid any potential negative effects of testing.

At the meeting, participants were again asked if they understood the participant information sheet and during this time the lead researcher checked again to ensure that the participant had mental capacity to consent to take part. If it was decided that they had capacity, participants were asked to sign a consent form (Appendix I). The lead researcher then worked through the questionnaire booklet with the participant. Regular breaks were offered to participants to prevent fatigue. Following completion of the questionnaire, a debrief was given by the lead researcher and participants were given the chance to ask any questions. They were also asked if they wanted feedback of the findings. If they did, their contact details were collected on a separate sheet of paper, which were kept separate to their responses. They were also asked to provide details of their GP and/or healthcare worker so that a letter could be sent to them informing them of the participant's involvement in the study (Appendix J). Participants were thanked for their time and informed of an approximate date of when to expect the feedback if requested.

In the next section, the plans for analysing the data in the present sample are described.

2.6 Plan of Analysis

All analyses were carried out using Statistical Package for the Social Sciences (SPSS). Descriptive statistics were used to analyse the demographic information, and the mean scores and standard deviations on the SQ, SDMT, MMSE and HADS were computed. Checks for normal distribution were performed on all variables, as well as reliability and validity checks for the measures used.

Preliminary analyses were carried out using correlation coefficient tests to determine associations between the length of time since diagnosis and MMSE scores and all variables of interest. Correlational analyses were performed to check for comparisons between dementia groups (AD group and combined VaD and mixed dementia) on all variables of interest, as well as checking for difference in age and MMSE scores.

The main analyses for all research questions involved using parametric or non-parametric tests of correlations (Pearson's product moment correlation coefficient or Spearman's rank correlation coefficient), depending on the normal distribution of variables. Primary hypotheses were analysed using one-tailed tests and secondary (exploratory) hypotheses with two-tailed tests. There was no missing data in the dataset. An alpha level of .05 was used for all statistical tests, other than when adjusting for Bonferroni corrections. The latter procedure was determined by dividing .05 by the number of comparisons being made.

Analyses involved separate correlations between: a) SQ (AI and AO self-discrepancies) and the HADS (total score, anxiety and depression) (Primary Research Question 1), b) the SDMT (AM specificity) and the depression score on the HADS (Primary Research Question 2), c) the SDMT (AM integration) and the total score on the HADS (Primary Research Question 3), c) the SQ (AI and AO self-

discrepancies) and all scores on the SDMT (AM specificity, AM fluency, AM integration and AM lifetime period [childhood and early adulthood lifetime periods]) (Secondary Research Question 1), and d) the number of reported dementia-related self-attributes and the total score on the HADS (Secondary Research Question 2).

Additional analyses were also performed using a one-sample t-test to compare the mean score on AM specificity in the current sample to that of a healthy older adults group. Comparisons between AI and AO self-discrepancies scores in the present sample were also computed using a paired-samples t-test.

3. Chapter Three - Results

3.1 Chapter Overview

This chapter will first outline the descriptive statistics for all the measures used in the current study. Information on normal distribution checks will then be presented, along with reliability and validity checks for relevant measures. Preliminary and comparative analyses will then be summarised, followed by the data analyses for all research questions and hypotheses. Additional analyses will also be outlined. The chapter will conclude with a summary of the overall results.

3.2 Descriptive Statistics

Descriptive statistics for scores on self-discrepancies (AI and AO) and dementia-related self-attributes (SQ-DRSA) (all measured by the SQ) are presented in Table 5. Descriptive statistics for AM scores (as measured by the SDMT) for: 1) fluency (SDMT-F), 2) specificity (SDMT-S), 3) integration (SDMT-I), and 4) lifetime period (childhood [SDMT-LP(C)] and early adulthood [SDMT-LP(EA)]) are also outlined in Table 5. Emotional distress was examined using the total score and separate anxiety and depression scores on the HADS (hereafter referred to as HADS-T, HADS-A and HADS-D, respectively). Descriptive statistics for these scores can also be found in Table 5.

In the current study just under half of the sample (45.4%) reported symptoms suggestive of an anxiety disorder (i.e., scores above the normal range) and just under one fifth (18.1%) reported symptoms suggestive of a depressive disorder (i.e., scores above the normal range). In relation to cognitive functioning (as measured by the MMSE), participants' scores ranged from 18 to 28 ($M = 22.30$, $SD = 3.34$). On the SQ, participants' scores ranged from -2 (self-consistency) to 5 (self-discrepancy).

Table 5

Means and Standard Deviations for Self-Discrepancies, Autobiographical Memory, and Emotional Distress

	<i>M</i>	<i>SD</i>
AI self – discrepancies	0.60*	4.82
AO self – discrepancies	-2.12*	3.89
SQ-DRSA	1.88	1.78
SDMT – S	2.15	1.43
SDMT – I	0.12	0.33
SDMT – F	119.90	61.55
SDMT – LP(C)	1.84	1.32
SDMT – LP(EA)	1.60	1.02
HADS – T	11.24	5.35
HADS – D	4.36	2.79
HADS – A	6.87	3.49

Note. $n = 33$

* Scores above zero denote self-discrepancy and scores below zero represent self-consistency.

3.3 Normal Distribution Checks

The normal distribution of all variables of investigation were checked by visually examining histograms and assessing skewness and kurtosis. Z-scores were calculated for all variables using skewness and kurtosis figures (by dividing each value by its standard error) and measured to ascertain if they were above $z = 1.96$. Values exceeding this number are considered to be significantly different from a normal distribution (Field, 2009). The majority of variables met the assumptions for normal distribution, except those measuring AI and AO self-discrepancies, dementia-related self-attributes, and SDMT-I. These variables were all positively skewed.

For positively skewed data, it has been suggested that the data can be converted to within normal distribution parameters by using a logarithm

transformation technique (Pallant, 2010). However, this technique was not possible for these variables due to the data containing either or both zero and negative values. Where outliers were identified in these variables they were either changed or left unaltered depending on how much influence they had on the overall distribution. A total of four outliers for the variables measuring AI and AO self-discrepancies, and one outlier for SQ-DRSA were considered to be significantly skewing the overall data. Therefore, these outliers were altered and converted the data to within normal distribution limits. This was done by using a method outlined in Field (2009), which involved changing the scores of the outliers to be one unit above the next highest score in the data set.

Transformation of the data for SDMT-I was unsuitable given the considerable number of zero values in the data, and was therefore left unchanged. Thus, analyses involving AM integration were performed using non-parametric tests. Analyses of all other variables were conducted using parametric tests.

3.4 Reliability and Validity Checks

3.4.1 Reliability of the HADS

Cronbach's alpha coefficient (α) was calculated for the current sample ($n = 33$) and was found to be .80 for the total scale, .79 for the anxiety subscale, and .65 for the depression subscale. It has been recommended that α values should be at least .60 for a self-report instrument to be reliable (Nunnally & Bernstein, 1994), although scores above .70 and .80 are considered preferable (Kline, 1999). The α values for the current sample therefore indicate adequate to good internal consistency. These scores are also consistent with previous research involving older adults (e.g., Flint & Rifat, 2002).

3.4.2 Inter-Rater Reliability of the SDMT and SQ

Inter-rater reliability for specificity and integration was assessed on the SDMT, and for AI and AO self-discrepancies and dementia-related self-attributes on the SQ. An independent rater coded 20% of the questionnaires. The rater was blind to the research questions and hypotheses. Agreement for specificity and integration was found to be good (Kappa coefficients = .71 and .88, respectively). Coding of AI and AO self-discrepancies and dementia-related self-attributes also achieved very good agreement (Kappa coefficients = .87, .96, and .87, respectively). According to Peat (2001), a Kappa value of .70 represents good agreement and .80 indicates very good agreement. Therefore, the Kappa values found for the current study were in the good to very good range.

3.4.3. Discriminant Validity of the SQ

In light of findings that have found a high correlation between AI and AO self-discrepancies (e.g., Tangney et al., 1998), Pearson's product-moment correlation coefficients were performed to compare the scores on AI and AO self-discrepancies in the current study. A significant correlation was found between the two scores ($r = .70, p < .001$, two-tailed), indicating that higher levels of AI self-discrepancies were associated with greater AO self-discrepancies. This suggests that in the current sample, AI and AO self-discrepancies may not be independent constructs, as would be expected on the SQ.

3.5 Preliminary Analyses

3.5.1 Comparisons between all Variables of Investigation and the Length of Time since Diagnosis and Cognitive Functioning

Pearson's product moment correlation coefficients were carried out to determine if there were any associations between the SDMT (SDMT-F, SDMT-S,

SDMT-I, SDMT-LP(C), SDMT-LP(EA)), the HADS (HADS-T, HADS-A, and HADS-D), the SQ (AI and AO self-discrepancies, and SQ-DRSA), and the length of time since diagnosis and cognitive functioning (as measured by the MMSE) (Table 6). This was done in order to determine if the length of time since diagnosis or cognitive functioning needed to be controlled for in subsequent analyses. For SDMT-I a non-parametric test of correlation (Spearman's rank correlation coefficient) was used. Bonferroni correction for multiple comparisons was applied at alpha level .002. No significant relationships were found between any sections on the SDMT, HADS and SQ, and the length of time since diagnosis and MMSE scores following Bonferroni correction. Therefore, the latter two were not considered in subsequent analyses.

Table 6

Correlations between Length of Time since Diagnosis and MMSE Scores and All Variables of Investigation

	MMSE		Length of Time Since Diagnosis	
	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
MMSE	-	-	-.25	.15
Length of time since diagnosis	-.25	.15	-	-
AI self-discrepancies	.46	.006	-.11	.54
AO self-discrepancies	.06	.72	-.14	.41
SQ-DRSA	.39	.02	.19	.28
SDMT-S	.08	.65	-.13	.47
SDMT-I	-.12	.47	.10	.57
SDMT-F	-.01	.93	-.17	.33
SDMT-LP(C)	-.12	.49	-.00	.98
SDMT-LP(EA)	.15	.39	.08	.63
HADS-T	.35	.04	-.24	.17
HADS-D	.21	.22	-.25	.15
HADS-A	.36	.03	-.16	.36

Note. $n = 33$

Two-tailed tests.

3.6 Comparative Analyses

3.6.1 Comparisons between Dementia Groups by Diagnosis on all Variables of

Interest

To explore any differences between participants based on their diagnosis of dementia, participants with AD ($n = 23$) were compared to those with VaD and mixed dementia combined ($n = 10$) on all variables, as shown in Table 7. This was carried out to determine if subsequent analyses needed to be conducted based on dementia type (i.e. as two different groups). As some of the variables used in this comparison were not normally distributed, a two-tailed, non-parametric t-test (Mann-Whitney U) was performed (adjusted for Bonferroni correction at alpha level .001).

The analyses revealed no significant differences between the two groups on any variables following Bonferonni correction. Therefore, all subsequent analyses were carried out as a whole group.

Table 7

Comparison of Means and Standard Deviations for the Alzheimer's disease and Combined Vascular and Mixed Dementia Groups

	AD Group Mean (SD) <i>n</i> = 23	Combined VaD and Mixed Dementia Group (SD) <i>n</i> = 10	<i>U</i>	<i>p</i>
Age	77.00 (6.02)	79.00 (5.12)	97.50	.49
MMSE	22.48 (3.27)	21.90 (3.64)	103.00	.63
Length of time since diagnosis	17.30 (17.08)	14.40 (12.74)	112.50	.92
AI self-discrepancies	1.65* (4.37)	-1.80* (5.20)	65.50	.04
AO self-discrepancies	-1.69* (3.66)	-3.10* (4.43)	89.50	.31
SQ-DRSA	1.83 (1.80)	2.00 (1.82)	107.50	.76
SDMT-S	2.00 (1.28)	2.50 (1.78)	91.00	.33
SDMT-I	0.17 (0.39)	0.00 (0.00)	95.00	.16
SDMT-F	106.04 (56.38)	151.80 (63.88)	67.50	.06
SDMT-LP(C)	1.91 (1.20)	1.70 (1.64)	96.00	.44
SDMT-LP(EA)	1.70 (1.20)	1.40 (1.08)	96.00	.43
HADS-T	10.30 (5.46)	13.40 (4.67)	79.00	.15
HADS-D	3.87 (2.87)	5.50 (2.37)	76.50	.12
HADS-A	6.43 (3.51)	7.90 (3.41)	86.50	.26

Note. * Scores above zero denote self-discrepancy and scores below zero represent self-consistency.

3.7 Analyses for Research Questions and Hypotheses

3.7.1. Primary Research Question 1: Is there a Relationship between Self-Discrepancies and Emotional Distress in People with Mild Dementia?

In order to test hypotheses for Primary Research Question 1, Pearson's product moment correlations coefficients were calculated to investigate the

relationship between AI and AO self-discrepancies and the three emotional distress scores (HADS-T, HADS-A, and HADS-D). Separate analyses were performed for each hypothesis. Bonferroni correction was set at alpha level .025 for Primary Hypothesis 1. The results of these analyses are presented in Table 8.

3.7.1.1 Primary hypothesis 1: Greater self-discrepancies (as indicated by AI and AO self-discrepancies) will be related to higher levels of overall emotional distress. There was a significant positive correlation found between AI self-discrepancies and overall emotional distress, indicating that greater discrepancies between actual and ideal self-attributes were significantly associated with higher levels of overall emotional distress (combined anxiety and depression). However, there was no significant association found between AO self-discrepancies and overall emotional distress, although the relationship was in the predicted direction (see Appendix K, Figures 2 and 3, for a graphical representation).

3.7.1.2 Secondary hypothesis 1: Higher AI self-discrepancies will be associated with higher levels of depression. No significant correlation was found between AI self-discrepancies and levels of depression, although the relationship was in the predicted direction. However, there was a significant association between AI self-discrepancies and levels of anxiety, in that more discrepancy between actual and ideal self-attributes were significantly associated with increased levels of anxiety.

3.7.1.3 Secondary hypothesis 2: Higher AO self-discrepancies will be associated with higher levels of anxiety. No significant relationship was found between AO self-discrepancies and levels of anxiety, although the relationship was in the predicted direction. There was also no significant correlation between AO self-discrepancies and levels of depression.

3.7.2 Summary

Analyses revealed a significant positive relationship between AI self-discrepancies and overall emotional distress. However, no significant association was found between AO self-discrepancies and overall emotional distress, although the relationship was in the expected direction. No significant relationships were found between AI self-discrepancies and depression, or AO self-discrepancies and anxiety. However, AI self-discrepancies were significantly associated with anxiety. These results show mixed outcomes in relation to the predicted hypotheses.

Table 8

Correlations between Emotional Distress and Scores on Self-Discrepancies and Autobiographical Memory

	HADS-T		HADS-D		HADS-A	
	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
AI self-discrepancies	.35	.022	.22	.11	.36	.03**
AO self-discrepancies	.22	.10	.21	.22**	.17	.16
SQ-DRSA	.48	.004**	-	-	-	-
SDMT-S	.07	.33	-.20	.12	-	-
SDMT-I	-.30*	.04	-	-	-	-

Note. $n = 33$

* Spearman's Rho correlation (non-parametric).

** Two-tailed tests.

3.7.3 Primary Research Question 2: Is there a Relationship between OGM and Depression in People with Mild Dementia?

Pearson's product-moment correlation coefficient (one-tailed) was carried out to test the hypothesis for Primary Research Question 2. This analysis involved comparing total scores on the SDMT-S (number of specific memories recalled) to scores on the HADS-D (Table 8).

3.7.3.1 Primary hypothesis 2: Recall of fewer specific memories will be associated with higher levels of depression. No significant correlation was found

between OGM and depression (see Appendix K, Figure 4, for a graphical representation). However, the correlation was in the predicted direction, in that recall of fewer specific memories was related to higher depression scores.

3.7.4 Summary

The analysis revealed that OGM was not significantly correlated with depression. However, as predicted, the correlation was towards recall of fewer specific memories and higher levels of depression. Nevertheless, this finding does not support the predicted hypothesis.

3.7.5 Primary Research Question 3: Is there a Relationship between AM Integration and Emotional Distress in People with Mild Dementia?

Given that AM integration was not normally distributed, a one-tailed, non-parametric test of correlation was used (Spearman's rank correlation coefficient) to test the hypothesis for Primary Research Question 3. This involved comparing total scores on the SDMT-I (number of integrative memories recalled) with scores on overall emotional distress (HADS-T) (Table 8).

3.7.5.1 Primary hypothesis 3: Recall of fewer AM integrative memories will be associated with higher levels of overall emotional distress. A significant relationship was found between the number of integrative memories recalled and overall emotional distress, in that recall of fewer integrative memories was associated with higher levels of overall emotional distress (see Appendix K, Figure 5, for a graphical representation).

3.7.6 Summary

The analysis showed a significant relationship between the number of AM integrative memories recalled and overall emotional distress. Therefore, these findings provide support for the predicted hypothesis.

3.7.7 Secondary Research Question 1: Is there a Relationship between Self-Discrepancies and AM in People with Mild Dementia?

In order to test the hypotheses for Secondary Research Question 1, separate two-tailed, Pearson's product-moment correlation coefficients were conducted. Analyses involved comparing AI and AO self-discrepancies with: a) AM specificity (SDMT-S), b) AM fluency (SDMT-F), c) AM integration (SDMT-I), and d) AM childhood and early adulthood lifetime periods (SDMT-LP(C) and SDMT-LP(EA)) (Table 9). As SDMT-I was not normally distributed, two-tailed, Spearman's rank correlation coefficients were used to compare these scores to AI and AO self-discrepancies. Bonferroni correction for multiple comparisons was set at alpha level .025 for Secondary Hypotheses 3, 4 and 5, and .012 for Secondary Hypothesis 6.

3.7.7.1 Secondary hypothesis 3: Greater self-discrepancies (as indicated by AI and AO self-discrepancies) will be associated with recall of fewer specific memories. Analyses revealed no significant relationships between the number of specific memories recalled and either AI or AO self-discrepancies.

3.7.7.2 Secondary hypothesis 4: Greater self-discrepancies (as indicated by AI and AO self-discrepancies) will be associated with lower levels of AM fluency. No significant correlations were found between AI and AO self-discrepancies and AM fluency.

3.7.7.3 Secondary hypothesis 5: Greater self-discrepancies (as indicated by AI and AO self-discrepancies) will be associated with recall of fewer integrative memories. There were no significant relationships between AI and AO self-discrepancies and recall of integrative memories.

3.7.7.4 Secondary hypothesis 6: Greater self-discrepancies (as indicated by AI and AO self-discrepancies) will be associated with recall of

fewer AM memories from the childhood and early adulthood lifetime periods.

No significant correlations were found between AI and AO self-discrepancies and the number of AM memories recalled from the childhood or early adulthood lifetime periods. There was a trend towards a negative relationship between AO self-discrepancies and recall of AM memories from the childhood lifetime period, but this did not reach statistical significance.

3.7.8 Summary

Analyses revealed that there were no significant relationships between AI and AO self-discrepancies and any AM variables (specificity, fluency, integration, or childhood and early adulthood lifetime periods). There was a trend towards a negative association between AO self-discrepancies and recall of AM memories from the childhood lifetime period, but this did not reach statistical significant. Therefore, these results do not support the predicted hypotheses.

Table 9

Correlations between Self-Discrepancies and Autobiographical Memory

	AI self-discrepancies		AO self-discrepancies	
	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
SDMT-S	.01	.94	.04	.79
SDMT-F	-.12	.47	.01	.94
SDMT-I	-.13	.45	-.08	.62
SDMT-LP(C)	-.14	.41	-.30	.09
SDMT-LP(EA)	-.00	.99	.01	.91

Note. n = 33

3.7.9 Secondary Research Question 2: Is there a Relationship between Dementia-Related Self-Attributes and Emotional Distress in People with Mild Dementia?

To explore Secondary Research Question 2, Pearson's product-moment correlation coefficients were used to compare scores on the SQ-DRSA (the number of reported dementia-related self-attributes) and scores on overall emotional distress (HADS-T) (Table 8).

3.7.9.1 Secondary hypothesis 7: Greater dementia-related self-attributes will be associated with higher levels of overall emotional distress. The analysis revealed that there was a significant positive correlation between the number of reported dementia-related self-attributes and overall emotional distress, indicating that more reported dementia-related self-attributes were associated with higher levels of overall emotional distress.

3.7.10 Summary

The results showed that there was a significant positive relationship between the number of reported dementia-related self-attributes and overall emotional distress.

3.8 Additional Analyses

3.8.1 Normative Comparisons for OGM

In view of the seemingly average scores on AM specificity in the current sample, a one-sample t-test was performed to compare the present mean with that of a normative age-matched sample. The mean score on AM specificity in the current sample was ($M = 2.15, SD = 1.43$), while the mean score on AM specificity found in healthy older adults was ($M = 2.27, SD = 1.79$) (Singer, Rexhaj, & Baddeley, 2007). These mean scores were not statistically significant ($t(32) = -0.47, p = .639$, two-tailed), suggesting that the scores on AM specificity in the present sample did not differ from those of a healthy older adults sample.

3.8.2 Comparisons between AI and AO Self-Discrepancies

Descriptive statistics revealed that AO self-discrepancies were lower ($M = -2.12$, $SD = 3.89$) than AI self-discrepancies ($M = 0.60$, $SD = 4.82$) in the current sample. In order to determine if these scores were significantly different, a paired-samples t-test was carried out. The results showed that these scores were significantly different ($t(32) = 4.50$, $p < .001$, two-tailed), indicating that AI self-discrepancies were significantly higher than AO self-discrepancies in the current sample.

3.9 Overall Summary of Results

In this chapter, descriptive statistics were presented, along with information about normal distribution checks. Reliability and validity checks of the measures used were performed and were mostly adequate, although the discriminant validity of the SQ was found to be questionable due to the overlap between scores on AI and AO self-discrepancies. Preliminary analyses revealed that there were no significant correlations between the length of time since diagnosis and cognitive functioning and any of the variables of investigation. Comparative analyses also indicated that there were no significant differences between the AD and the combined VaD and mixed dementia groups on any of the variables of interest.

For the main results, correlational analyses were performed to examine the relationships between AI and AO self-discrepancies and emotional distress (anxiety, depression and overall emotional distress); AI and AO self-discrepancies and AM (specificity, fluency, integration, and lifetime period); AM (specificity and integration) and emotional distress (depression and overall emotional distress); and dementia-related self-attributes and overall emotional distress.

As expected, a significant positive association was found between AI self-discrepancies and overall emotional distress, but this was not the case for AO self-discrepancies. However, this was in the predicted direction. No significant relationships were found between AI self-discrepancies and depression, or AO self-discrepancies and anxiety, although there was a significant positive correlation between AI self-discrepancies and anxiety. Analyses also revealed that, as predicted, there was a negative relationship between recall of AM integrative memories and overall emotional distress. However, OGM was not found to be significantly associated with depression, although the findings were in the anticipated negative direction.

Results indicated that there were no significant associations between AI and AO self-discrepancies and any scores on AM. However, there was a trend towards a negative association between AO self-discrepancies and memories recalled from the childhood lifetime period, but this did not reach statistical significance. Analyses further revealed a significant positive relationship between the number of reported dementia-related self-attributes and overall emotional distress.

Finally, the results of additional analyses showed that AI self-discrepancies were significantly higher than AO self-discrepancies in the current sample. Furthermore, comparison of the mean score on AM specificity from the present sample to that of healthy older adults revealed that OGM was not significantly different in the current sample. Therefore, in total, the current findings provide partial support for some of the predicted hypotheses. The results from the present study will be discussed in the following chapter.

4. Chapter Four - Discussion

4.1 Chapter Overview

This chapter will discuss the main findings of the current research in relation to the existing literature. A summary of the findings with theoretical implications will then be outlined, followed by a discussion of the clinical implications of the current study. The research process will then be discussed, including a critical review of the methodology and some reflections on the research process. Finally, suggestions for future research will be described and a conclusion of the present study will be presented.

4.2 Primary Research Question 1: Is there a Relationship between Self-Discrepancies and Emotional Distress in People with Mild Dementia?

4.2.1 Discussion of the Findings

In the present study it was hypothesised that greater AI and AO self-discrepancies would be significantly correlated with higher scores on combined anxiety and depression (overall emotional distress). It was also predicted that higher AI self-discrepancies would be associated with greater levels of depression, while greater AO self-discrepancies would be related to higher scores on anxiety. The results from the current study provide some support for Primary Hypothesis 1, in that a significant positive relationship between AI self-discrepancies and overall emotional distress was found. This indicates that greater discrepancy between the actual and ideal self-guides was significantly associated with higher levels of overall emotional distress. However, no significant association was found between AO self-discrepancies and overall emotional distress, although the relationship was in the predicted direction. Moreover, no significant relationships were found between AI self-discrepancies and levels of depression, or AO self-discrepancies and levels of

anxiety. Therefore, no support was found for Secondary Hypotheses 1 or 2 in the present study. However, there was a significant positive correlation between AI self-discrepancies and anxiety. This suggests that in the current study, more discrepancy between the actual and ideal self-attributes was significantly associated with higher levels of anxiety.

The present study was the first to examine self-discrepancies and emotional distress in PWD. The current findings do not support the disorder specific contentions of Higgins' (1987) SDT, which proposes that AI self-discrepancies are associated with dejection-related emotions, such as depression, while AO self-discrepancies are related to agitation-related emotions, such as anxiety. However, the support for SDT (Higgins, 1987) is contentious. While some studies have found associations between particular self-discrepancies and specific types of emotional distress (e.g., Scott & O'Hara, 1993; Strauman, 1992), others have found no support for the distress specificity tenets of SDT (Higgins, 1987), but instead for an association between self-discrepancies and negative affect in general (e.g., Ozgul et al., 2003; Tangney et al., 1998).

The results of the current study are consistent with these findings as AI self-discrepancies were found to be positively associated with overall emotional distress. They are also in line with research which has found personal identity strength to be critical in predicting well-being in PWD (e.g., Jetten et al., 2010). Moreover, Burch et al. (2000) found no association between AO self-discrepancies and anxious affect, which is in line with the findings of the present study. In a review of SDT, Arena (2008) suggested that the evidence to date indicates a more generalised association between self-discrepancies and emotional distress. The results of the present study appear to lend support to this proposition. Additionally, the finding in the current

study that more discrepancy between the actual and ideal self-guides was significantly correlated with higher levels of anxiety provides support for a more global association between self-discrepancies and emotional distress. It also suggests that depression may not have been particularly prevalent in current sample, hence the absence of any findings indicating a relationship between depression specifically and self-discrepancies.

However, it is important to note that this finding, and the failure to identify the specific associations between self-discrepancies and different types of emotional distress, may in part also be due to difficulties with the measurement of self-discrepancies using the SQ (Higgins et al., 1985). Indeed, in order to find unique relationships, there must be evidence to suggest that these exist in the first instance. In the present study, the inter-correlations between AI and AO self-discrepancies on the SQ were high ($r = .70, p < .001$), suggesting that they may not be tapping into different constructs. Similar results have been found in previous studies using the SQ (e.g., Tangney et al., 1998), and also in Higgins et al. (1985) original paper, with inter-correlations ranging from $r = .53-.80$ between AI and AO self-discrepancies. These high inter-correlations between AI and AO self-discrepancies suggest poor discriminant validity of the SQ. More recently, Rodebaugh and Donague (2007) have also questioned the robustness of the SQ and alternative measures for assessing self-discrepancies have been put forward (e.g., Francis, Boldero, & Sambell, 2006).

In the current study, it was found that AO self-discrepancies were significantly lower ($M = -2.12, SD = 3.89$) than AI self-discrepancies ($M = 0.60, SD = 4.82$). This suggests that there was more consistency between actual and ought self-states than actual and ideal self-states in the present sample. This may be one reason why there were no significant associations between AO self-discrepancies

and emotional distress. Another possibility for why AI self-discrepancies were higher in the current sample than AO self-discrepancies is the way in which the SQ was administered. For example, actual self attributes were requested first, then ideal self attributes, followed by ought self attributes. It was recognised by Tangney et al. (1998) that generating new and different adjectives of self-assessment over several pages may be over-taxing and lead to participants losing sight of subtle distinctions in the different self-states. This may be even more pertinent in a dementia population, given the cognitive difficulties associated with the disease.

An alternative explanation for higher AI self-discrepancies found in the current study may be because ideal self-states were more dominant than ought self-states. This is acknowledged by Higgins (1987) in his theory, whereby he proposed that some people may only possess one self-guide, which they will be more motivated to meet. It is conceivable that ideal self-guides (i.e., ultimate goals for oneself) may be more germane in a group of people with mild dementia than ought self-guides (i.e., normative rules or prescriptions for oneself) because of the incongruence between their actual and ideal selves in the face of the adverse effects that their dementing illness may be having on their lives. Ought self-guides may be more grounded in morality and therefore less affected in dementia than goal-orientated self-guides.

One other possible explanation for the low AO self-discrepancy scores in the present study and therefore a non-significant association with emotional distress may be related to the coping strategies adopted by PWD. Indeed, Clare (2003) found that individuals' sense of their self varied in terms of their reaction to the changes associated with the experience of dementia. She proposed that these ranged from "self-maintaining" (i.e., working to maintain an existing identity), to "self-adjusting"

(i.e., developing a new sense of self by incorporating changes into their new identity). Some of the findings of this study appear to be consistent with the “self-maintaining” strategy, in that some people in the current sample may have been protecting themselves from having to update and adjust to these identity changes, rather than integrate them into their new sense of self.

Similarly, Naylor and Clare (2008) argue that PWD, as result of AM impairments, may fail to update the store of personally-relevant information (i.e., the PDB) (Morris & Hannesdottir, 2004), thereby reducing the extent to which the sense of self is challenged by perceived changes in functioning and abilities. This is based on the tenets of the Cognitive Awareness Model (Morris & Hannesdottir, 2004), which links awareness of memory functioning with AM and indirectly with the self. Naylor and Clare (2008) assert that this inability to update the PDB may result in psychological defence mechanisms in order to preserve their prior sense of self. Some of the results of the current study appear to support these claims, as reflected in the low scores on AO self-discrepancies. Indeed, this finding is more conducive to self-consistency between the actual and ought self-states, rather than self-inconsistency, as proposed by SDT (Higgins, 1987).

4.3 Primary Research Question 2: Is there a Relationship between OGM and Depression in People with Mild Dementia?

4.3.1 Discussion of the Findings

It was hypothesised in the current study that OGM (i.e., impaired recall of specific memories) would be associated with higher levels of depression. No support was found for Primary Hypothesis 2. However, although not significant, the relationship between AM specificity and depression was in the predicted direction, in

that recall of fewer specific memories was associated with higher levels of depression.

One explanation for these findings is that OGM was not particularly pronounced in the current sample. For example, the mean score on AM specificity was $M = 2.15$, $SD = 1.43$. This mean is comparable to AM specificity found in healthy older adults ($M = 2.27$, $SD = 1.79$) (Singer et al., 2007). Both scores were not statistically significant, suggesting that the participants in this sample were no more deficient in AM specificity than healthy older adults. Therefore, given that impaired recall of specific memories is typically related to affective disorders (e.g., Williams et al., 2007), it may be plausible that a relationship was not detected in the present sample due to the relatively average levels of AM specificity. The small sample size in the current study may also be a reason for not identifying significant relationships between OGM and depression. Another possibility may be that the sample in the present study was not particularly depressed. Indeed, typical levels of depression seen in PWD range from 30 to 50% (e.g., Taylor et al., 2003), while in the current sample only 18.1% of people showed signs suggestive of a depressive disorder. It is important to consider that studies exploring the link between OGM and depression have typically been carried out on samples of people who are already depressed (e.g., Barnhofer, Jong-Meyer, Kleinpass, & Nikesch, 2002; Kremers, Spinhoven, & Van der Does, 2004). Therefore, given the seemingly low levels of depression in the present sample it may not have been possible to detect such relationships.

The findings from the current study in relation to low levels of AM specificity are inconsistent with those of Moses et al. (2004), who found a significant deficit in the retrieval of specific memories in PWD, compared to healthy controls.

However, although no correlations were made between depression and OGM in this study, the authors did measure depression using the Geriatric Depression Scale-15 (Sheikh & Yesavage, 1986) and found no evidence of depression in their sample. These findings are similar to the current study, whereby relatively low levels of depression were found in comparison to other studies measuring depression in PWD (e.g., Taylor et al., 2003).

Although OGM appeared to be lacking in the current sample, which is contrary to the findings of Moses et al. (2004), the comparison of the means between the current study and that of Moses et al. was not possible due to different measures being used to assess OGM (these authors used the Autobiographical Memory Test; Williams & Broadbent, 1986). Indeed, the differences in measurement may, to some extent, account for the dissimilar findings, as well as the small sample size used in Moses et al. study ($n = 10$).

4.4. Primary Research Question 3: Is there a Relationship between AM Integration and Emotional Distress in People with Mild Dementia?

4.4.1 Discussion of the Findings

It was predicted in the current study that recall of fewer integrative memories would be associated with higher levels of overall emotional distress. The results from the present study found a significant negative relationship between integrative memories and overall emotional distress, therefore supporting Primary Hypothesis 3. These findings suggest that the inability to engage in meaning-making from autobiographical memories is associated with combined anxiety and depression.

This is consistent with Blagov and Singer's (2004) proposition that meaning-making and the construction of integrative self-defining memories are strategies that help people to cope with negative emotions. Indeed, in the current study it appears

that for some participants, the incapacity to ascribe meaning to their memories is associated with emotional distress. That is, they made limited linkage between their memories and the lessons they learned from them in relation to the self or individual growth and change (Singer & Blagov, 2000-2001).

Integrative memories have been examined in healthy older adults, whereby it was found that the recall of integrative memories were higher in older adults than college students (Singer et al., 2007). The mean score for these older adults was $M = 2.29$, $SD = 1.87$. This is substantially higher than the mean score found in the current sample ($M = 0.12$, $SD = 0.33$) and suggests that deficiencies in integrative memories may be associated with the effects of dementia. Indeed, Wong & Watt (1991), who explored a taxonomy of reminiscence in older adults, suggested that integrative reminiscence (i.e., accepting one's past as worthwhile [Butler, 1963], resolving the disparity between ideal and reality [Birren, 1964], and accepting negative life events and reconciling past conflicts [Lieberman & Tobin, 1983]) and instrumental reminiscence (i.e., drawing from past experiences to solve present problems) was associated with more adaptive ageing. They further proposed that this may be related to positive self-schemata, which is consistent with Ross's (1989) premise that personal memories are guided by the self-schemata that one possesses in the present.

The finding in the current study between fewer integrative memories and higher levels of emotional distress is also in line with the proposals of Bauer et al. (2008), who argue that stories which involve growth and development are linked to higher levels of emotional well-being. The lack of integrative memories retrieved by the present sample suggests that PWD may struggle to access or generate memories that incorporate growth and development. In view of findings which indicate that

older people retrieve more integrative memories than college students (e.g., Singer et al., 2007), it may be something specific about the experience of dementia that prevents integrative remembering. For example, this could be attributable to the cognitive dysfunction that accompanies dementia. Indeed, given that meaning-making from memories requires a separate cognitive process to generic life review (e.g., Blagov & Singer, 2004), it may be this cognitive overload that is too demanding for PWD.

Further exploration of the relationship between integrative remembering and emotional distress in PWD using larger samples and a control group may assist with delineation of the findings in the current study. However, although this finding was significant even when using a non-parametric statistical test, it should be treated with some caution due to the limited variability in the scores measuring integrative memories, which may inflate the correlation coefficient.

4.5 Secondary Research Question 1: Is there a Relationship between Self-Discrepancies and AM in People with Mild Dementia?

4.5.1 Discussion of the Findings

In the present study it was hypothesised that greater AI and AO self-discrepancies would be significantly associated with more deficiencies in AM (i.e., OGM, lower levels of AM fluency, recall of fewer integrative memories and retrieval of fewer memories from the childhood and early adulthood AM lifetime periods). No significant relationships were found between AI and AO self-discrepancies and any aspects of AM in the current study. Therefore, these findings do not support the current hypotheses.

The results did show a trend towards higher AO self-discrepancies and fewer memories recalled from the childhood lifetime period, but this did not reach

statistical significance . Nonetheless, this trend is consistent with the reminiscence bump phenomenon (e.g., Rathbone et al., 2008) and arguments that autobiographical memories from the childhood to early adulthood timeframes (ages 10-30) are crucial to the formation of the self and identity (e.g., Conway, 1997; Fitzgerald, 1988).

The finding that AI and AO self-discrepancies were not related to OGM in the current sample is unsurprising given that OGM did not appear to be particularly problematic in this sample, compared to healthy older adults. Indeed, the mean score on AM specificity in the current sample indicates that nearly half of all the AM memories retrieved (out of five) were specific. Reasons for these seemingly high scores are outlined in sections 4.2.1 and 4.3.1 and similarly apply here for possible explanations as to why OGM was not related to self-discrepancies in the present study.

However, it is more surprising that there was no association between integrative memories and AI and AO self-discrepancies in the present study given the overall low number of integrative memories retrieved in the current sample. It would be expected that deficiencies in the recall of integrative memories would be related to impairments in the self and identity given the role they play in providing the construction of a life story that uses the past to inform a sense of identity (Blagov & Singer, 2004). However, one explanation for this finding may be to do with the measurement difficulties of the SQ described in section 4.2.1. Moreover, conceptualising aspects of the self and identity are problematic (Caddell & Clare, 2010), and it is possible that other measures of the self and/or identity may detect such a relationship.

The findings of the current study are inconsistent with the SMS (Conway & Pleydell-Pearce, 2000), which proposes a reciprocal relationship between AM and

the self, in that AM serves to maintain the self, while the goals of the working self function to activate AM. They are also contrary to previous research that has found an association between AM deficits and impairments in the self and identity in PWD (e.g., Addis & Tippett, 2004; Fargeau et al., 2010; Jetten et al., 2010). For instance, Addis and Tippett (2004) found that deficits in autobiographical fluency for childhood events and early adulthood names were related to a weaker identity, but no such relationship was found in the present study. However, these studies used different measures to assess AM and the self, making direct comparisons problematic. The study by Fargeau et al. (2010) also only found a significant correlation between personal semantic fluency and not episodic fluency, the latter of which was only explored in present study. Nevertheless, the results of the current study are in line with those of Naylor and Clare (2008) who found no relationship between AM and identity in PWD.

Explanations for the non-significant findings between AM and self-discrepancies in the current study may again be related to measurement and conceptualisation issues as highlighted by Caddell and Clare (2010), and also due to the problems with the SQ as summarised in section 4.2.1. Additionally, the small sample size in the study may have prevented significant associations from being found.

Alternatively, another possible reason for not finding a relationship between self-discrepancies and AM is that the hypotheses may be inaccurate. Indeed, the link between the self and AM in PWD, although theoretically supported by the SMS (Conway & Pleydell-Pearce, 2000), is still relatively under-researched and the findings are equivocal. It is possible that self-discrepancies may not tap into the dimensions of the self that are most associated with AM. That is, SDT (Higgins,

1987) is a theory based on self-incompatibility, whereas aspects of the self in other studies exploring the link between identity and AM in dementia (e.g., Addis & Tippett, 2004; Naylor & Clare, 2008) are underpinned by theories of self-coherence, which is the element of the self that is purported to be important in the SMS (e.g., Conway, 2005). It is feasible then that self-incompatibility may not be as conducive to decline as self-coherence in PWD if it is less associated with AM. Similarly, it may be that self-discrepancies are not pertinent in dementia, particularly if psychological defence mechanisms are at play to protect the self (e.g., Clare, 2003; Naylor & Clare, 2008). However, in total, the multi-faceted nature of the self and identity makes delineation of the findings in this, and previous studies, challenging.

4.6 Secondary Research Question 2: Is there a Relationship between Dementia-Related Self-Attributes and Emotional Distress in People with Mild Dementia?

4.6.1 Discussion of the Findings

In the present study, a significant relationship was found between a higher number of reported dementia-related self-attributes and greater levels of combined anxiety and depression. This is consistent with the SRM (Leventhal et al., 1984) of adjustment to illness, in which it is proposed that in order to make sense of their illness people develop illness representations, which subsequently influence emotional and coping responses. Among others, these illness cognitions incorporate beliefs about illness identity (i.e., the label and perceived symptoms of their illness). A strong illness identity in people with a chronic illness has been found to be associated with higher levels of depression and anxiety (e.g., Vaughan et al., 2003). The results of the current study are in line with these findings, in that people who defined their current self-concept in terms of their dementing illness (i.e., who had a

stronger illness identity) in the current sample tended to experience higher levels of emotional distress.

It appears that, to some degree, the changes associated with dementia have been incorporated into the current self-concept for some people in the current study, which is in line with Clare's (2003) findings of a self-adjusting strategy. This indicates that some people in the current sample may have been fairly aware of their difficulties, and were therefore more likely to experience emotional distress. This is consistent with previous findings which have showed that increased awareness of difficulties due to being in the milder phases of dementia are related to higher levels of emotional distress (e.g., Aalten et al., 2005; Brierley et al., 2003; Holtzer et al., 2005).

However, these results should be regarded tentatively due to the way in which dementia-related self-attributes were measured. It is acknowledged that these were not assessed using any standardised coding procedure and differ to methods used to examine illness representations in other studies. Nevertheless, inter-rater reliability from a blind rater did indicate very good agreement for this variable and these findings do provide preliminary results which are worthwhile of further exploration.

In the next section, a summary of the overall current findings in relation to previous research will be outlined, as well as theoretical implications.

4.7 Summary of the Current Findings in Relation to the Extant Literature and Theoretical Implications

The findings of the current study are mixed. Some relationships between AM, the self and emotional distress are consistent with previous research, while others do not appear to support the existing literature.

The present findings are consistent with SDT to some degree, although they do not support the disorder-specificity contentions of the theory. However, the specific relationships between AI self-discrepancies and depression, and AO self-discrepancies and anxiety have been refuted by several authors, who contend that self-discrepancies are associated with negative affect in general. The results of this study tend to lend support to this argument. Therefore, while it appears that SDT may be a useful framework in which to understand emotional distress in people with dementia, based on the current research and previous findings, a revision may be necessary which accounts for a general self-discrepancy model in relation to emotional distress more broadly.

Deficiencies in integrative memories were the only relevant AM deficit in the current study that was associated with emotional distress. This is in line with previous research which has suggested that the failure to ascribe meaning to one's memories is associated with adjustment difficulties. However, no support was found for a significant relationship between OGM and depression in the current sample, although the relationship was in the predicted direction. These findings are contrary to those of a large body of research which has found a link between OGM and depression. Yet, this may be because OGM and depression was not particularly pronounced in the current sample, therefore making it unlikely that a relationship between the two would be detected. The lack of OGM found in the current sample is inconsistent with some other research that has found OGM in PWD, although this research was based on a very small sample and used a different method for assessing OGM to the measure used in the present study (e.g., Moses et al., 2004).

No significant relationships were found between AM deficits and self-discrepancies in the current study, although there was a trend towards greater AO

self-discrepancies and less recall of memories from the childhood lifetime period. The latter finding is consistent with previous research on the reminiscence bump phenomenon and studies that have implicated the childhood timeframe in the formation of the self. Therefore, impairments in memory from this period are likely to have the most negative impact on the sense of self. Although this relationship did not reach significance in the current study, it does warrant further investigation. If a significant relationship were to be found in the future this would lend further theoretical support to the reminiscence bump phenomenon and its unique relationship with the self. However, the lack of other significant findings between AM and the self is partially inconsistent with previous research, which suggests an association between integrative memories and the self, and AM fluency and the self. Indeed, the findings from the current study do not lend support to the SMS model of the self and AM, although it should be noted that the findings in the current study should be treated with some degree of caution due to the methodological issues which have already been outlined, and which will be discussed further in section 4.8.

Finally, the current findings did show an association between greater dementia-related self-attributes (i.e., a stronger illness identity) and higher levels of emotional distress. This is consistent with other research which has found that certain illness representations (e.g., a strong illness identity and beliefs about limited control over one's illness) are related to increased levels of depression and anxiety. Therefore, these findings lend support to the contentions of the SRM and would therefore be worthwhile of further investigation.

The next section will describe the clinical implications of the current research, including suggestions for future interventions.

4.8 Clinical Implications

Although preliminary, some of the findings from the current study may have several important clinical implications. For example, given the findings that recall of fewer integrative memories was associated with higher levels of emotional distress, it may be useful to develop or adapt existing interventions for PWD to incorporate sessions which focus on the development of an integrative style of reminiscence. This could potentially be integrated into current approaches such as CST groups, reminiscence therapy, or life review. In the same vein, Serrano Latorre, Gatz, and Montanes (2004) examined the efficacy of life review based on autobiographical retrieval practice for treating older people with depression and found significant reductions in depression post-treatment in comparison to controls. However, it is recognised that further research is necessary before adapting current techniques. Further research may therefore take the form of comparing integrative based reminiscence to unguided reminiscence or a control group. In doing so, it may be determined whether this approach will result in higher levels of emotional well-being.

In view of the findings in the current study which indicate that greater AI self-discrepancies and dementia-related self-attributes were related to increased levels of emotional distress, it may be beneficial for clinicians to focus on techniques that assist PWD in maintaining self-consistency (i.e., by helping to preserve their sense of self prior to the onset of dementia). This may be achieved by first determining the important roles or attributes that individuals feel they have, or had, and using strategies to maximise these. This may be done with the help of a carer to ascertain the most salient features that make up an individual's sense of self. Activities which assist with maintaining these roles or self-attributes, such as helping

others or doing work-related tasks, could then be used to bolster the sense of self. A similar intervention encapsulating these ideas has been devised but is still in a preliminary stage (see Romero & Wenz, 2001). In light of the important links between thoughts, emotions and behaviour (e.g., Kuyken, 2005) it may also be useful for clinicians to use a cognitive-behavioural approach to explore any thoughts regarding self-discrepancies that PWD may have and then utilise behavioural techniques to address these.

Some of these types of interventions may be provided by either clinicians or carers of PWD. Indeed, given that others are seen to be integral to the way one sees oneself (e.g., Cooley, 1902), which may be particularly pertinent with regards to carers who are relatives of PWD, it may be helpful to assist carers in using techniques which help PWD to maintain their sense of self. This is consistent with Kitwood's personhood model (1990, 1996, 1997), in which he contends that having a sense of continuity with the past (a self-narrative) is crucial in meeting the needs of PWD.

The next section will outline the limitations of the current study, including issues with sampling and the design of the study. Problems with the measures used and data collection will also be discussed in addition to reflections of the research process.

4.9 Research Process

4.9.1 Critical Review of Methodology

Several methodological issues need to be considered when interpreting the findings of the present study. First, although the current study was adequately powered according to G*Power (Faul et al., 2007), it is possible that significant effects were unable to be detected given the small sample size. Moreover, larger

sample sizes are generally preferred in research (Field, 2009). It is noteworthy, however, that the sample size in the present study is comparable to other studies in this area of research (e.g., Addis & Tippett, 2004; Naylor & Clare, 2008).

Second, as the design of the study was correlational in nature, it is not possible to determine causality. That is, it cannot be ascertained if dementia-related self-attributes and deficits in integrative memories and AI self-discrepancies are the cause of emotional distress or vice versa. Similarly, it cannot be determined if greater AI self-discrepancies cause anxiety and depression or whether it is anxiety and depression that create more AI self-discrepancies. Additionally, it cannot be ruled out that these relationships may be attributable to a third variable, such as physical illness or life events. In order to overcome this, longitudinal designs with larger samples are necessary to investigate AM, the self and emotional distress in PWD.

Third, in order to avoid making Type 1 errors as a result of producing multiple comparisons, Bonferroni corrections were employed for all relevant statistical tests. This meant that some significant findings at alpha level .05 were missed. To avoid needing to make multiple comparisons, future research should consider limiting the number of variables of investigation. Furthermore, using a larger, more homogenous sample of PWD, with less variability in cognitive functioning and dementia diagnosis, may also prove useful in overcoming these difficulties.

Fourth, the current study employed a convenience sample of PWD that was predominately made up of males and none of whom were diagnosed with clinical depression or anxiety. This may have been problematic for several reasons. For example, as already outlined in section 4.3.1, the majority of research examining the

relationship between OGM and depression has used samples that are already depressed. In view of this, and the additional aims of the present study to explore relationships between self-discrepancies, AM and emotional distress in PWD, it may have been more beneficial to select a sample of PWD who were already experiencing emotional distress. Subsequently, the relationships between these variables may have been more likely to be detected. Moreover, the gender imbalance in the sample may have attributed to the relatively low levels of depression in the sample because males may reject difficult emotions when faced with them (e.g., Kinglerlee, 2012) and therefore may under-report or minimise their distress. This may be even more pertinent given that emotional distress was assessed using a self-report measure, which are notorious for response biases (e.g., Hammond, 2000).

Fifth, as documented in section 4.2.1, there were some concerns with the SQ measure for assessing self-discrepancies in the current sample. In addition to these issues, the applicability of the SQ to measure self-discrepancies in dementia may be questionable as it is not specifically validated for use with this population. Indeed, although the SQ has been used in older adults before (e.g., Francis et al., 2002; Heidrich & Powwattana, 2004), the present study is the first to use it in PWD.

The inherent difficulties in using self and identity tasks with PWD have been highlighted by Addis and Tippett (2004) and Naylor and Clare (2008) who used the TSCS-II (Fitts & Warren, 1996) and TST (Kuhn & McPartland, 1954) to measure identity in dementia groups. Indeed, Addis and Tippett proposed that frontal dysfunction in dementia may produce impairments in generation of responses, fluency, and retrieval processes, which may be necessary when responding to identity tasks, such as articulating one's sense of self. However, they argue that

these types of deficiencies cannot necessarily be equated with a change in a person's subjective sense of who they are.

Nevertheless, these impairments, which may be particularly relevant in relation to the SQ because of its idiographic approach, may have led to difficulties in responding to the SQ in the current sample. For example, the lead researcher observed many participants struggling to articulate adjectives in order to complete this task. Additionally, by the time participants had reached the ought self attributes list at the end, responses typically had begun to diminish, which may be one possible account for the lower AO self-discrepancies found in the current sample.

Moreover, given that participants provided attributes verbally on the SQ to the lead researcher, this may have led to certain participant biases, such as the Hawthorn effect or demand characteristics. The former involves participants responding more favourably to questions because they know they are directly being studied (Roethlisberger & Dickson, 1939). Similarly, the latter refers to participants modifying their responses in line with what they think the researcher wants (Orne, 1962). These biases may be particularly pertinent when assessing aspects of the self. The issues relating to the assessment of dementia-related self-attributes according to the SQ are also important to be considered, which were discussed in section 4.8.1.

Finally, it is noteworthy that the SDMT has not been used with PWD before and therefore required some modification during the research process. For example, although the SDMT only requires the retrieval of five memories from any timeframe, which is less onerous than the AMI which requires retrieval of nine memories from three specific timeframes, it became clear during the research process that some participants found it too cognitively demanding to take in all of the instructions. Therefore, it was necessary for the lead researcher to simplify or improvise the

instructions where required. Moreover, sometimes it was necessary to prompt an individual to recall a memory or carers would simultaneously do this for the person. Nevertheless, the lead researcher attempted to keep this to a minimum. These alterations may have been problematic for several reasons. First, by shortening the instructions specific qualities necessary to obtain a self-defining memory may have been missed out, and this is also a departure from the standardised method. Second, the necessity to prompt individuals may have acted as a primer to recount certain types of memories, or resulted in more memories being retrieved than would have done left unprompted. This may account, to some extent, for the high number of specific memories recalled in the present sample.

4.9.2 Reflections on the Research Process

It is important to note that the current study underwent several changes from the initial research proposal. First, regression analyses were planned to determine the factors that may predict emotional distress in PWD. However, due to the small sample size obtained this was not possible. If more time and resources were available to conduct the current study, the small sample size may have been overcome. Second, additional variables were considered for inclusion in the study, including BPSDs and QOL, but it was decided that this was too broad for the scope of this study given the allocated timeframes for completion.

Numerous challenges throughout the research process should also be noted. In particular, recruiting PWD proved extremely difficult due to staff time constraints in the recruiting OPCMHTs and lack of consent from prospective participants. It is for these reasons that issues with the size and composition of the sample arose. As discussed in section 4.3.1, measuring self-discrepancies in PWD was also problematic and led to several modifications of the original measures (e.g., asking

participants to talk out aloud when recalling their memories as opposed to writing them down on the SDMT). This measure and the SQ were also time-intensive and participants struggled to complete them without prompting. For these reasons, it would be beneficial for prospective researchers to carefully consider sampling and measurement selection in future studies investigating self-discrepancies, AM and emotional distress in PWD.

The next section will describe some possible directions for future research based on the findings of the current study.

4.10 Suggestions for Future Research

As this was the first study to explore the relationships between AM, the self and emotional distress in people with mild dementia, future research would benefit from examining these relationships further with a larger, more homogenous and gender-balanced sample of PWD. Specifically, in view of the findings in the current study which showed that deficiencies in integrative memories were associated with emotional distress, future research may be useful to explore this relationship further. It may also be worthwhile for future research to investigate the relationship between different aspects of the self and identity (or self-discrepancies using a different measure) and integrative memories in people with mild dementia given that no relationship was found between the two variables in the current study. Measures that incorporate both participants' and informants' views (e.g., a carer) may provide a useful insight into these areas, as well as improve the robustness and ecological validity of results.

Similarly, as this was the first study to examine self-discrepancies in PWD, and AI self-discrepancies were found to be associated with overall emotional distress, it may be a valuable area for prospective investigation. However, although

it seemed appropriate to start with the SQ in research with dementia groups, as it was the original measure for self-discrepancies, given the problems documented with it in sections 4.2.1 and 4.9.1, it may be useful for future research to attempt to use different approaches. Some alternative measures are available to measure self-discrepancies, including the Self-Lines measure (Francis et al., 2006) and a modified version of the SQ (Rodebaugh & Donahue, 2007), although these measures are still in the preliminary stages of being tested for their psychometric properties.

Another possible measure which may be used in further research is the Head Injury Semantic Differential III (HISD-III; Tyerman & Humphrey, 1984). Although it is a measure designed to assess self-discrepancies in people with head injury, it may be suitable to be adapted for use in PWD in view of the similar difficulties found among these two groups (e.g., cognitive deficits and adjustment difficulties) (e.g., Wilson & Gracey, 2009). The HISD-III enables the assessment of pre-injury self, current self and ideal self. It may be feasible to modify this to use with PWD by substituting pre-injury self with pre-diagnosis self. This measure may also be less cognitively taxing for PWD given that adjectives are already supplied, placing less onerous on participants to produce self-attributes using free recall. However, echoing the view of Naylor and Clare (2008), future research would benefit from identifying the optimal methods for measuring the self and identity in PWD.

In view of the sampling issues in the current study, future research should consider using a sample of emotionally distressed PWD, which may increase the likelihood of detecting significant relationships between self-discrepancies, AM and emotional distress. Moreover, it may prove fruitful for future studies to use regression analyses to explore the factors that may be associated with emotional distress in PWD. This should enable the most salient factors that contribute to

emotional distress to be established and therefore assist in shaping interventions to help alleviate emotional distress in PWD.

Finally, in the current study it was observed during the research process that many participants recalled emotive and negative memories. Previous research has suggested that individuals who are depressed have more difficulty in using positive autobiographical memories for mood repair (Josephson, Rose, & Singer, 1999–2000; Rusting & DeHart, 2000). Therefore, given that 18.1% of the current sample reported depressive symptoms, it may be fruitful for future research to measure the affect of self-defining memories in PWD to determine if negative tone in memories is indeed related to depression. This could have important clinical implications if a relationship is found in terms of assisting PWD to retrieve positive autobiographical memories via life review approaches.

The following section will outline the overall conclusions of the present study.

4.11 Conclusion

The current study is the first to investigate the relationships between AM, self-discrepancies and emotional distress in PWD. The findings from the present study add to the existing literature exploring the emotional impact of dementia by providing preliminary evidence in three areas. First, they indicate that AI self-discrepancies are associated with emotional distress in people with mild dementia, suggesting that incongruence between the actual self (self-concept) and ideal self-states are related to higher levels of combined anxiety and depression. Second, they suggest that emotional distress in people with mild dementia is related to deficits in AM, namely in the form of impaired recall of integrative memories. This indicates that the inability to produce meaning from autobiographical memories is associated

with higher levels of emotional distress. Third, they show that more dementia-related self-attributes (i.e., a stronger illness identity) are associated with higher levels of emotional distress. That is, the more an individual describes themselves in terms of their dementing illness, the more likely they are to experience emotional distress.

The overall findings of this study suggest that PWD may cope with the disease by using strategies that lie somewhere on a continuum between self-adjusting and self-maintaining (Clare, 2003), and which consequently may either mediate or moderate emotional distress. Indeed, for individuals who experienced AI self-discrepancies and reported more dementia-related self-attributes, it is possible that they were using a self-adjusting strategy (i.e., by incorporating the changes associated with dementia into their current self-concept), which may in fact induce emotional distress. However, given that emotional distress did not appear to be as strongly related to AO self-discrepancies in the current sample, it is plausible that, to some extent, participants were adopting a psychological defence mechanism or self-maintaining strategy (Clare, 2003; Naylor & Clare, 2008), which may serve to protect against emotional distress. The current findings therefore have theoretical implications for the application of SDT, narrative models of autobiographical memory and the self, and the SRM of adjustment to illness in the understanding of emotional distress in PWD.

However, whatever the association between AM, the self and emotional distress in PWD, it is clear that the relationships are far from straightforward. In light of this, and similar to the study by Jetten et al. (2010), future research may attempt to identify and explore other factors that may mediate or moderate emotional distress in people with mild dementia.

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Appendices

- Appendix A: Invitation Letter to Services
- Appendix B: Participant Information Sheet
- Appendix C: Poster Advertisement for the Study
- Appendix D: Consent to Contact Form
- Appendix E: Norfolk Research Ethics Committee Approval Letter
- Appendix F: Demographic Information Sheet
- Appendix G: Selves Questionnaire (SQ)
- Appendix H: Self-defining memory task (SDMT)
- Appendix I: Participant Consent Form
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- Appendix K: Scatterplots for Primary Hypotheses

Appendix A
Invitation Letter to Services

January 2011

Dear Sir/Madam,

Re: Psychological Research in Dementia – A Request for Participants

I am a trainee clinical psychologist undertaking a Doctorate in Clinical Psychology at the University of East Anglia. I am writing to you to highlight some research that I am conducting from January to May 2011 exploring the factors that may be associated with emotional distress in people with mild dementia.

This project aims to contribute to psychological understanding of the experiences of people with dementia. It is also hoped that it will go on to inform future interventions to help people with dementia. I would like to request clients that you feel may be interested in taking part in the study and who may be suitable in light of the inclusion criteria (please see attached). I have also attached a Participant Information Sheet, which provides detailed information about what the study involves. The research has received ethical approval from Norfolk Research Ethics Committee.

It would be helpful if I could arrange a time to come and speak to your team to talk about the research and hand out some Participant Information Sheets for staff to pass on to interested and suitable clients. It would also be useful if I could put up a poster advertising the study in your waiting room(s) (please see attached).

If you would like to find out more about the study, please call me on xxx or email me at L.Christoforou-Hazelwood@uea.ac.uk I will contact you again shortly to see when it may be convenient to come and speak with your team and to see if you are happy for me to advertise the study.

Many thanks for your time.

Best wishes,

Lorna Christoforou-Hazelwood

Trainee Clinical Psychologist

Supervised by Dr Laura Jobson, Clinical Psychologist & Lecturer, University of East Anglia

Appendix B
Participant Information Sheet

PARTICIPANT INFORMATION SHEET

An Exploratory Analysis of the Factors associated with Emotional Distress in People with Mild Dementia

You are being invited to take part in a research study. Before you decide whether you wish to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

Please ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

1. What is the purpose of the study?

The study is being conducted as part of my training in fulfilment of a Doctorate in Clinical Psychology at the University of East Anglia.

People who have dementia can experience a range of difficulties, which may affect the way that they feel. The aim of the current study is to explore whether a person's memory and their beliefs about themselves may affect their emotions.

2. Why have I been chosen?

You have been chosen because you have a mild form of dementia of the Alzheimer's, vascular or mixed type.

3. Do I have to take part?

No. It is your choice if you wish to take part. If you decide not to, your treatment or any service that you are receiving will not be affected in any way.

You can also withdraw from the study at any time and this will not affect your treatment or any service that you are receiving. However, if you do chose to withdraw from the study after you have taken part, it will not be possible to remove your data from the study.

4. What will happen to me if I do take part?

If you decide to take part I will first go through any questions that you may have about the study. I will also ask you some questions to check that you are suitable for the study.

If you choose to proceed, I will arrange a time and place that is convenient for you to complete the assessments which look at your memory, the beliefs you have about yourself and your emotions. You are welcome to have a friend or relative with you at the meeting.

At the beginning of the meeting I will ask you to complete a Consent Form indicating that you are still happy to participate.

To assist healthcare professionals in knowing about the study, a letter will also be sent to your key healthcare/support worker (where applicable) and your General Practitioner (GP) to inform them about your participation in the study. A copy of this letter will be shown to you.

The whole meeting should take approximately 60-70 minutes. Some assessments require you to answer questions on your own and others will involve a brief structured interview with me. I will be with you for the whole duration to answer any questions.

5. What are the possible risks or disadvantages of taking part?

It is unlikely that there will be any adverse risks to you for taking part in the study. However, if you feel that completing the assessments has caused you any distress, I will be available to talk about any concerns you may have.

If this is not sufficient I would advise you to talk to your key healthcare/support worker (where applicable) or visit your GP.

6. What are the possible benefits of taking part?

The benefits to taking part in the study are helping to contribute to psychological understanding of the factors that may influence emotional distress in people with mild dementia.

The findings may also be used to inform future treatments to help people with dementia.

7. Will my taking part in this study be kept confidential?

All of the information collected about you will be kept strictly confidential and will only be seen by myself and my research supervisor, Dr Laura Jobson.

You will not be able to be identified from any information that you give. Storage and use of information in this study will be fully compliant with the Data Protection Act.

8. What will happen to the results of the research study?

Following completion of the assessments, I will write a report about the research, which will be published.

You will not be able to be identified from any information in this report.

You will be given the opportunity to be sent a summary of the findings of the study if you wish.

9. Complaints

If you have any concerns about the study, please first contact me (my details are below).

If you remain unsatisfied and wish to complain formally about the way you have been approached or treated in the study, you can do this through the NHS Complaints Procedure.

You may also contact your local NHS Patient Advice and Liaison Service (PALS) for any advice concerning the study.

0800 279 7257 (Norfolk)

0800 376 0775 (Cambridge & Peterborough)

0800 585544 (Suffolk)

10. Who has reviewed the study?

The study has been reviewed by Norfolk Research Ethics Committee and has received ethical approval.

11. Contact details

For further information about this study, please contact the researcher:

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Fax: 01603 593604

Mobile: xxx

Email: L.Christoforou-Hazelwood@uea.ac.uk
L.Jobson@uea.ac.uk

Thank you for taking the time to read this information sheet.

If you decide to participate in the research, you will be given a copy of this sheet to keep.

Appendix C

Poster Advertisement for the Study

RESEARCH INTO THE
PSYCHOLOGICAL
UNDERSTANDING OF EMOTIONAL
DISTRESS IN MILD DEMENTIA



**Would you like to take part in a study
looking at memory, identity and emotions?**

Who should take part?

We are looking for people who:

- have a mild form of dementia of the Alzheimer's, vascular or mixed type
- are already receiving care from a clinical service for their dementia

Interested?

If you are interested in taking part in the study, or would like further information, please contact Lorna Christoforou-Hazelwood (Trainee Clinical Psychologist) on: xxx or email me at: L.Christoforou-Hazelwood@uea.ac.uk

Appendix D
Consent to Contact Form

CONSENT FORM TO PASS ON CONTACT DETAILS

I agree for my contact details to be passed on to Lorna Christoforou-Hazelwood,
Trainee Clinical Psychologist, to be contacted by her for the purposes of her
research.

Name: _____

Contact Number: _____

Email address (if applicable): _____

Signature: _____

Date: _____

Name of Healthcare/Support Worker or GP (where applicable):

Signature: _____

Date: _____

Please return to: Lorna Christoforou-Hazelwood, C/O Karensa Rands, Senior
Administrative Assistant, Elizabeth Fry Building, Room 2.30, School of Medicine,
Health Policy and Practice, University of East Anglia, Norwich NR4 7TJ

Appendix E

Norfolk Research Ethics Committee Approval Letter



National Research Ethics Service

Norfolk Research Ethics Committee

Victoria House
Capital Park
Fulbourn
Cambridge
CB21 5XB

Telephone: 01223 597733
Facsimile: 01223 597645

23 November 2010

Mrs Lorna Christoforou-Hazelwood
Trainee Clinical Psychologist
Cambridgeshire & Peterborough NHS Foundation Trust
School of Medicine, Health Policy & Practice
University of East Anglia
Norwich
NR4 7TJ

Dear Mrs Christoforou-Hazelwood

Study Title: An Exploratory Analysis of the Factors Associated with Emotional Distress in People with Early-Stage Dementia
REC reference number: 10/H0310/52
Protocol number: N/A

Thank you for your letter of 18 October 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

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>.

This Research Ethics Committee is an advisory committee to East of England 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

Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation's involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.

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

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

Approved documents

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

Document	Version	Date
Covering Letter		14 August 2010
REC application		14 August 2010
Investigator CV Cl Lorna Chistoforou-Hazelwood		14 August 2010
Academic Supervisor CV Dr Laura Jobson		
Protocol	1	14 August 2010
Letter from Sponsor Email from Sue Steel		09 August 2010
Questionnaire: Hospital Anxiety and Depression Scale (HADS)		
Questionnaire: Study Specific Questionnaire	1	14 August 2010
Questionnaire: Selves Questionnaire	1	14 August 2010
Participant Consent Form	1	14 August 2010
Participant Consent Form: Participants' Healthcare Workers Contact Details Form	1	14 August 2010
Evidence of insurance or indemnity	Letter from UEA and Certificate from Zurich Municipal	16 June 2010
Referees or other scientific critique report	Marking Note from Kiki Mastrovannopoulou	01 June 2010
Response to Request for Further Information from Lorna Christoforou-Hazelwood		18 October 2010
Advertisement Poster	2	22 October 2010
Letter of invitation to participant - Letter to Service Providers	2	22 October 2010
GP/Consultant Information Sheets - Letter to Healthcare Worker	2	22 October 2010
GP/Consultant Information Sheets - GP letter	1	22 October 2010
Participant Information Sheet	2	22 October 2010
Questionnaire: Mini-Mental State Examination (MMSE)		
Questionnaire: Self-Defining Memory Task	2	22 October 2010

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.

This Research Ethics Committee is an advisory committee to East of England 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

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.

10/H0310/52 **Please quote this number on all correspondence**

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

Yours sincerely



PP **Michael Sheldon MA, PhD**
Chair

Email: Anna.Bradnam@eoe.nhs.uk

Encs: "After ethical review – guidance for researchers"

Cc: Mrs Tracy Moulton (Sponsor Contact)
R&D Department
University of East Anglia
Norwich
NR4 7TJ

Dr Laura Jobson (Academic Supervisor)
Cambridgeshire & Peterborough NHS Foundation Trust
School of Medicine, Health Policy & Practice
University of East Anglia
Norwich
NR4 7TJ

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the National Patient Safety Agency and Research Ethics Committees in England*

Appendix F

Demographic Information Sheet

Participant number: _____

Age: _____

Please answer the following questions about yourself (please tick where appropriate)

Are you?

Male

Female

What is your marital status?

How would you describe your ethnic origin?

What is your level of education?

Some secondary

GCSEs or O-Levels

A-Levels

Diploma

Undergraduate / Postgraduate

Are you in employment?

None

Voluntary

Paid

What type of dementia have you been diagnosed with?

Alzheimer's Disease

Vascular dementia

Mixed dementia

Do you have a carer?

Yes

No

If Yes, who is this?
(please tick all that apply)

Spouse

Child

Other relative

Friend

Paid carer

Other

If other, please state:

Where do you live?

At home

Residential Care Home

Other

If other, please state:

Who do you live with?
(please tick all that apply)

Spouse

Child

Other relative

Friend

Paid carer

Other

If other, please state:

What services are you currently using? (please tick all that apply)

Memory clinic	<input type="checkbox"/>
GP	<input type="checkbox"/>
Older People's Community Mental Health Team	<input type="checkbox"/>
Alzheimer's Society	<input type="checkbox"/>
Other charity (e.g., Age UK)	<input type="checkbox"/>
Residential Care	<input type="checkbox"/>
Day care centre	<input type="checkbox"/>
Other	<input type="checkbox"/>

If other, please state: _____

How long ago were you diagnosed with dementia?
(please state in months) _____ months

Have you ever suffered with a mental illness prior to being diagnosed with dementia?

Yes

No

If Yes, please state which mental illness:

Are you on any dementia medication?

Yes

No

If Yes, please state what:

Are you taking part in any other studies and/or interventions (e.g., dementia medication trial or Cognitive Stimulation Therapy)?

Yes

No

If Yes, please state what the study/intervention is called:

Appendix G
Selves Questionnaire (SQ)

Instructions

In the following questionnaire, you will be asked to list the attributes of the type of person you think you *actually*, *ideally*, and *ought* to be.

Actual self: Your beliefs concerning the attributes you think you *actually* possess.

Ideal self: Your beliefs concerning the attributes you would like *ideally* to possess; your ultimate goals for yourself.

Ought self: Your beliefs concerning the attributes you believe you *should* or *ought* to possess; your normative rules or prescriptions for yourself.

Please list 10 words that describe you (Actual self):				
	<i>Slightly</i>			<i>Extremely</i>
1	1	2	3	4
2	1	2	3	4
3	1	2	3	4
4	1	2	3	4
5	1	2	3	4
6	1	2	3	4
7	1	2	3	4
8	1	2	3	4
9	1	2	3	4
10	1	2	3	4

Now please circle a number above to indicate HOW MUCH each attribute you feel is like you (1 = *slightly*, 4 = *extremely*)

Ideal self: Your beliefs concerning the attributes you would like *ideally* to possess; your ultimate goals for yourself.

Please list 10 words that describe how you would ideally like to be (Ideal self):

	<i>Slightly</i>			<i>Extremely</i>
1	1	2	3	4
2	1	2	3	4
3	1	2	3	4
4	1	2	3	4
5	1	2	3	4
6	1	2	3	4
7	1	2	3	4
8	1	2	3	4
9	1	2	3	4
10	1	2	3	4

Now please circle a number above to indicate HOW MUCH of each attribute you feel you would like to have (1 = *slightly*, 4 = *extremely*)

Ought self: Your beliefs concerning the attributes you believe you *should* or *ought* to possess; your normative rules or prescriptions for yourself.

Please list 10 words that describe how you feel you ought to be (Ought self):

	<i>Slightly</i>			<i>Extremely</i>
1	1	2	3	4
2	1	2	3	4
3	1	2	3	4
4	1	2	3	4
5	1	2	3	4
6	1	2	3	4
7	1	2	3	4
8	1	2	3	4
9	1	2	3	4
10	1	2	3	4

Now please circle a number above to indicate HOW MUCH of each attribute you feel you ought to have (1 = *slightly*, 4 = *extremely*)

PLEASE NOW STOP AND TELL THE RESEARCHER YOU HAVE FINISHED.

Appendix H

Self-defining memory task (SDMT)

Instructions

This part of the task concerns the recall of a special kind of personal memory called a self-defining memory. A self-defining memory has the following attributes:

1. It is at least one year old.
2. It is a memory from your life that you remembered very clearly and that still feels important to you even as you think about it.
3. It is a memory about an important enduring theme, issue, or conflict from your life. It is a memory that helps explain who you are as an individual and might be the memory you would tell someone else if you wanted that person to understand you in a profound way.
4. It is a memory linked to other similar memories that share the same theme or concern.
5. It may be a memory that is positive or negative, or both, in how it makes you feel. The only important aspect is that it leads to strong feelings.
6. It is a memory that you have thought about many times. It should be familiar to you like a picture you have studied or a song (happy or sad) you have learned by heart.

To understand best what a self-defining memory is, imagine you have just met someone you like very much and are going for a walk together. Each of you is very committed to helping the other get to know the “Real You”. You are not trying to play a role or to strike a pose. While, inevitably, we say things that present a picture of ourselves that might not be completely accurate, imagine that you are making every effort to be honest. In the course of the conversation, you describe a memory that you feel conveys

powerfully how you have come to be the person you currently are. It is precisely this memory, which you tell the other person and simultaneously repeat to yourself, that constitutes a self-defining memory.

On the following pages you will be asked to recall and write 5 self-defining memories.

Please write down 5 self-defining memories that you can recall based on the instructions overleaf.

1. _____

Approximate date of above memory:

2. _____

Approximate date of above memory:

3. _____

Approximate date of above memory:

4.

Approximate date of above memory:

5.

Approximate date of above memory:

Please go back and recall your first self-defining memory. Using the rating scale below, please indicate how you felt today in recalling and thinking about your memory:

	0	1	2	3	4	5	6
	Not at all			Moderately			Extremely

1. Happy	0	1	2	3	4	5	6
2. Sad	0	1	2	3	4	5	6
3. Angry	0	1	2	3	4	5	6
4. Fearful	0	1	2	3	4	5	6
5. Surprised	0	1	2	3	4	5	6
6. Ashamed	0	1	2	3	4	5	6
7. Disgusted	0	1	2	3	4	5	6
8. Guilty	0	1	2	3	4	5	6
9. Interested	0	1	2	3	4	5	6
10. Embarrassed	0	1	2	3	4	5	6
11. Contemptful	0	1	2	3	4	5	6
12. Proud	0	1	2	3	4	5	6

Now please rate how vividly you recalled the memory:

Vivid	0	1	2	3	4	5	6
	Not at all			Moderately			Extremely

Now please rate how important the memory is to you:

Important	0	1	2	3	4	5	6
	Not at all			Moderately			Extremely

PLEASE MAKE SURE YOU HAVE NOT LEFT ANY ANSWERS BLANK
THANK YOU!

Appendix I
Participant Consent Form

PARTICIPANT CONSENT FORM

An Exploratory Analysis of the Factors associated with Emotional Distress in People with Mild Dementia

Lead researcher: Lorna Christoforou-Hazelwood, Trainee Clinical Psychologist
Supervised by: Dr Laura Jobson, Clinical Psychologist & Lecturer
Doctoral Programme in Clinical Psychology
School of Medicine, Health Policy and Practice
University of East Anglia

Please initial each box and sign at the bottom if you agree to participate.

1. I confirm that I have read and understand the information sheet dated _____ for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected.
3. I have been informed that the confidentiality of the information I provide will be safeguarded.
4. I understand that relevant sections of my data collected during the study may be looked at by individuals from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
5. I understand that a letter will be sent to my healthcare/support worker (where applicable) and my GP informing them of my participation in the study.
6. I agree to take part in the above study.

Name of Participant:

Signature:

Date:

If you decide to participate in the research, you will be given a copy of this sheet to keep.

Appendix J

Letter to GP / Healthcare Worker

Date: _____

Dear GP / Healthcare Worker,

**RE: Patient Participation in a Study Exploring the Factors Associated with
Emotional Distress in People with Mild Dementia**

I am writing to inform you that your patient, _____, has recently participated in a study exploring the factors associated with emotional distress for people who are suffering from mild dementia. The research is being conducted as part of my Doctoral research project at the University of East Anglia and has been approved by Norfolk Research Ethics Committee.

Taking part in the study involved participants' completing a questionnaire booklet, asking them about their memory, the beliefs they have about themselves and their emotions. Although participants should not have found these tasks distressing, they have been encouraged to contact you as their assigned GP/ healthcare worker GP if they do experience any distress. I am therefore advising you of your patient's participation in the study.

If you have any questions about this, or the research in general, please do not hesitate to contact me.

Best wishes,

Lorna Christoforou-Hazelwood
Trainee Clinical Psychologist
Supervised by Dr Laura Jobson, Clinical Psychologist & Lecturer (University of East Anglia)

Appendix K

Scatterplots for Primary Hypotheses

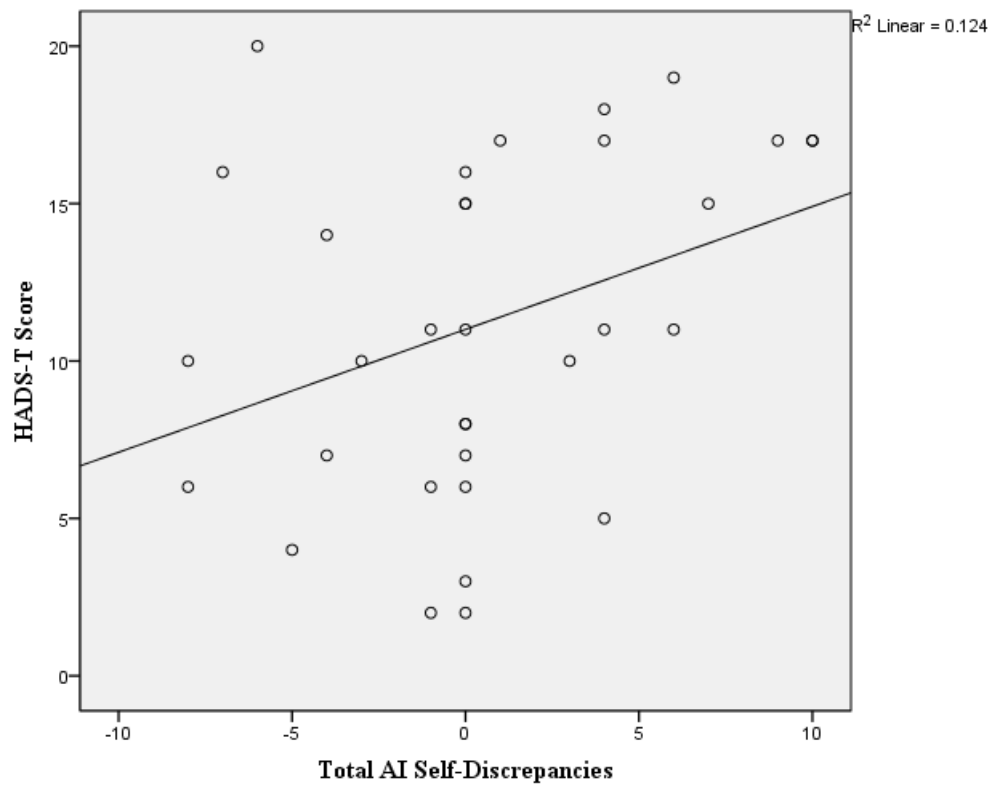


Figure 2. Scatterplot of total scores on the HADS and AI self-discrepancies

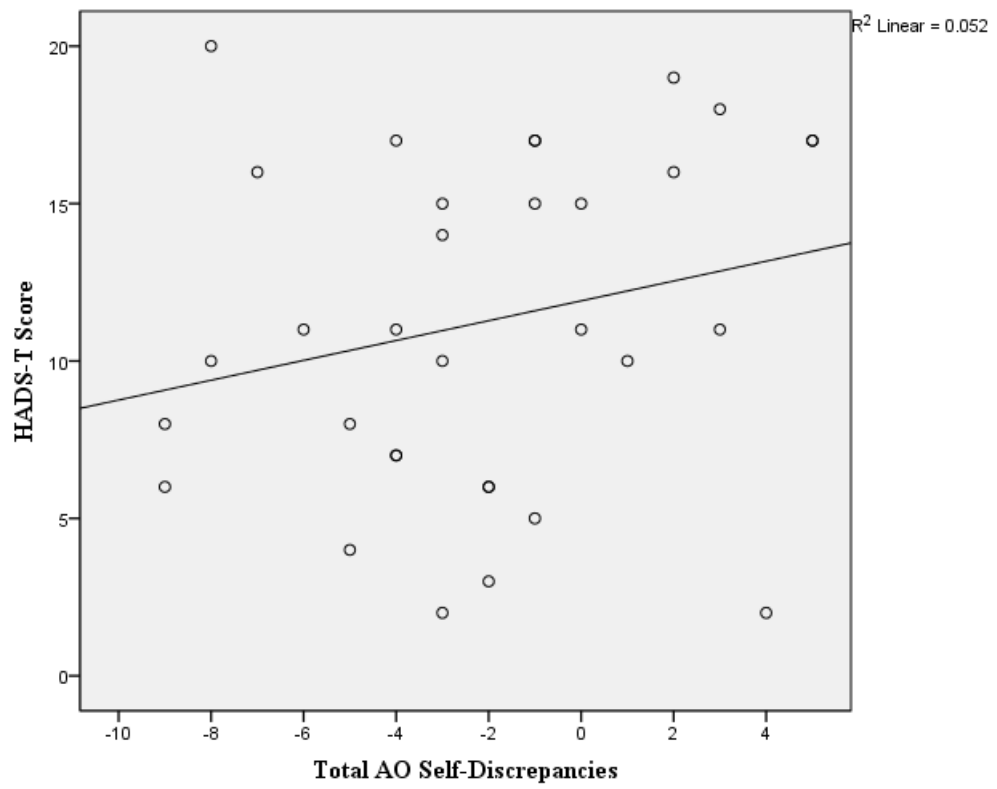


Figure 3. Scatterplot of total scores on the HADS and AO self-discrepancies

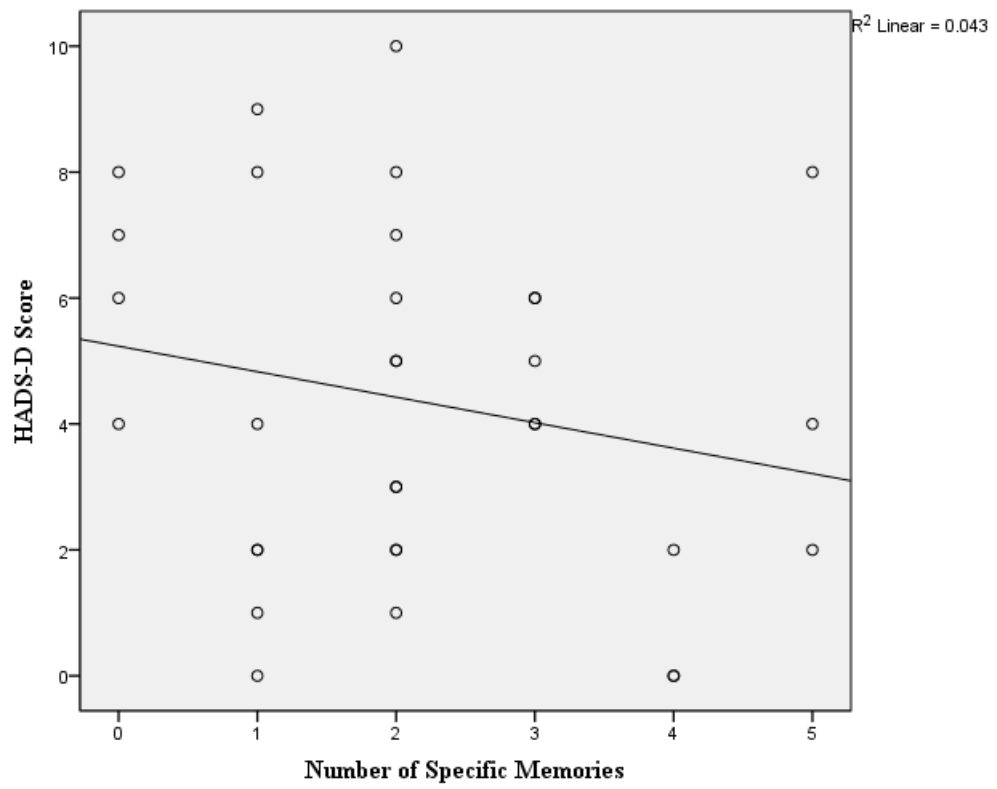


Figure 4. Scatterplot of depression scores on the HADS and AM specificity

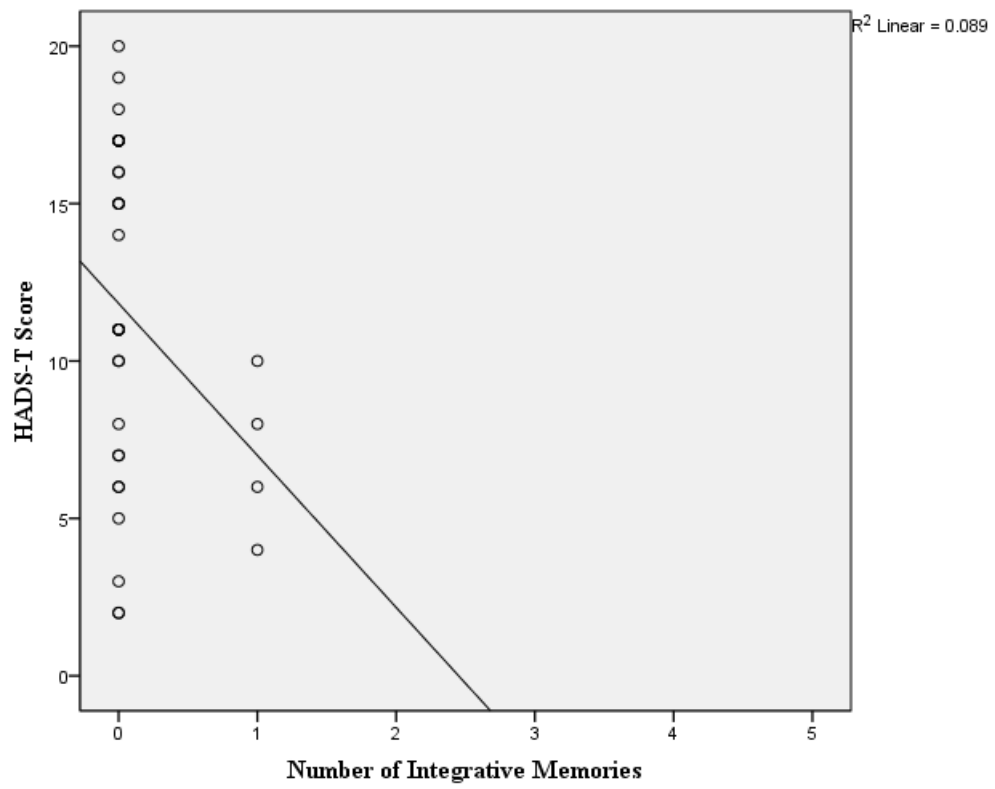


Figure 5. Scatterplot of total scores on the HADS and AM integration