Relationships between autobiographical memory, identity and awareness in early-stage dementia

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LARGE SCALE RESEARCH PROJECT

CONTENTS

SECTION ONE – ETHICS PROPOSAL

SECTION TWO – LITERATURE REVIEW

SECTION THREE – RESEARCH PAPER

SECTION FOUR – DISCUSSION PAPER

SECTION FIVE – WORD COUNT

Relationships between autobiographical memory, identity, and awareness in early-stage dementia.

ABSTRACT

This large-scale research project is presented in two parts. The first part constitutes a review of the literature relating to autobiographical memory and sense of self in early-stage dementia. It provides a brief overview of the theories that indicate how autobiographical memory and sense of self might be related, followed by a review of the changes observed in these constructs in association with early-stage dementia. Despite some empirical support, a limited amount of research has been conducted with regard to the relationship between autobiographical memory and aspects of self. This may reflect a number of conceptual and methodological difficulties. Also, changes in identity are often inferred by caregivers, based on changes in behaviour and abilities; the view of the person with dementia is rarely sought. Thus, identity change is usually considered in social rather than cognitive terms. Despite this, the hypothesised relationship between autobiographical memory and sense of self is utilised in psychosocial interventions, such as reminiscence.

The second part of this project examines the relationships between autobiographical memory, identity, and awareness within a sample of people with diagnoses of early-stage dementia. The 30 participants, recruited via a local memory clinic, were each administered the Autobiographical Memory Interview, Tennessee Self-Concept Scale, Second Edition, and Memory Awareness Rating Scale. Analysis using partial correlations, controlling for general cognitive ability, revealed that: greater recall of early adulthood personal semantic and incident memories was associated with more definite sense of identity, greater recall of mid-life incidents was associated with less definite identity but greater awareness, and greater awareness was associated with less definite identity. It is suggested that memories from the mid-life period may contain initial instances of awareness of changes in memory functioning, with greater awareness of change being associated with less certain identity, as knowledge about self is updated.

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SECTION ONE – ETHICS PROPOSAL

INTRODUCTION

This large-scale research project forms part of a larger, ongoing study led by Dr Linda Clare, entitled 'Understanding the experience of memory difficulties'. The aim of the larger project is to provide a comprehensive profile of awareness among people with mild to moderate dementia and mild cognitive impairment. This thesis examined the relationships between autobiographical memory, identity and awareness in a sample of people with early-stage dementia. What follows is the full ethical proposal for the overall study, along with the relevant documentation.

SECTION TWO – LITERATURE REVIEW

CONTENTS

Running head: autobiographical memory and sense of self

What are the implications of changes in autobiographical memory for sense of self in early-stage dementia?

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Abstract

This review examines the literature relating to autobiographical memory and sense of self in early-stage dementia. It provides a brief overview of the theories that indicate how autobiographical memory and sense of self might be related, followed by a review of the changes observed in these constructs in association with early-stage dementia. Despite some empirical support, a limited amount of research has been conducted with regard to the relationship between autobiographical memory and aspects of self. This may reflect a number of conceptual and methodological difficulties. Also, changes in identity are often inferred by caregivers, based on changes in behaviour and abilities; the view of the person with dementia is rarely sought. Thus, identity change is usually considered in social rather than cognitive terms. Despite this, the hypothesised relationship between autobiographical memory and sense of self is utilised in psychosocial interventions, such as reminiscence.

What are the Implications of Changes in Autobiographical Memory for Sense of Self in Early-Stage Dementia?

Autobiographical memory consists of stored information associated with the self (Brewer, 1986). It relates to major life goals, powerful emotions and personal meanings, and has therefore been seen as essential for the experience of personhood, i.e. of enduring as an individual over time (Conway & Pleydell-Pearce, 2000). Impairments of autobiographical memory have been observed in association with early-stage dementia, with systematic investigations having focused, primarily, on identifying the underlying cerebral structures (e.g. Levine, 2004), or on developing models of long-term memory storage (e.g. Westmacott, Leach, Freedman, & Moscovitch, 2001). However, the emergence of a new culture of dementia care (Kitwood, 1993, 1997), which emphasises the need to consider the individual experiences and biographies of people living with dementia, suggests that greater consideration be given to the subjective experience of those who are experiencing changes in their autobiographical memory, and the implications this has for care and interventions.

This review seeks to provide a brief overview of the theoretical literature on autobiographical memory and its relation to self, to explore the current state of knowledge with respect to the changes in autobiographical memory associated with early-stage dementia, and to consider the implications that these changes have for the subjective experience, in terms of impact on sense of self, of those in the early stages of the disease. Studies for inclusion in this review were identified by conducting searches of the computerised databases: PsychINFO; Medline; Web of Science; and the Cochrane Library. The term 'dementia' was coupled with the search terms:

autobiographical memory, self, and identity. These broad terms were chosen in order to gain the widest coverage possible, thus ensuring that all relevant studies were identified. No limit was applied to the period to be searched but it was specified that peer-reviewed journals and books in English were required.

How might autobiographical memory relate to self?

Autobiographical memory is a cognitive construct, currently conceptualised as comprising two relatively independent components, namely personal semantic memory and personal incident memory (e.g. Baddeley, 1992; Kopelman, Wilson, & Baddeley, 1989). Personal semantic memory refers to memory for personal factual information that is not contextually bound; whereas, personal incident memory is memory for specific personal events, which include detailed contextual information such as time and place (Addis & Tippett, 2004).

Three broad functions of autobiographical memory have been proposed (Bluck, Alea, Habermas, & Rubin, 2005): directive, social, and self. The directive function involves using the past to guide present, and future, thought and behaviour, with autobiographical memory serving as an aid to problem solving and supporting the development of attitudes and opinions. The social function concerns the sharing of personal memories in order to develop or maintain intimacy, to teach and inform, and to elicit and provide empathy. The self function is concerned with supporting a sense of continuity of self, and validating and supporting self-schemas.

Autobiographical memory appears to develop in early childhood, with representations of events experienced on more than one occasion, or single events of particular significance to the individual, being transferred from a temporary holding system of episodic memory into a longer lasting memory system (Nelson, 1993). A reliable distribution of autobiographical memories across the lifespan is elicited from healthy adult participants, using a variety of methods (Fitzgerald & Lawrence, 1984; Fromholt & Larsen, 1991). Rubin, Wetzler, & Nebes (1986) developed a three-component model reflecting this profile consisting of: a period of childhood amnesia with few memories; a reminiscence component, resulting in the overrepresentation of memories from early adulthood, termed 'the reminiscence bump', emerging after the age of about 35; and, after a reduction in the number of mid-life memories, an increased frequency of memories from the most recent years, accounted for by a retention component. It has been hypothesised that the reminiscence bump reflects the high accessibility of memories relating to this period, due to the original encoding conditions, in terms of events being emotionally laden, important, or self-relevant (Rubin et al., 1986). Many events are encountered for the first time in early adulthood and are distinctive due to their novelty and the effort involved in attributing meaning to them. This period also reflects a time of intense self-orientated activity, leading to the construction of a stable identity and life narrative (Fitzgerald, 1988, 1996, 1999).

In terms of the structure of autobiographical memory, Conway and Bekerian (1987) proposed three levels: lifetime periods, which are substantial periods of time defined by major ongoing situations; general events, which are repeated and/or extended events that cover a period of days to months; and event-specific knowledge, which comprises images, feelings and more specific details of general events. These levels are hierarchically-organised, with information relating to lifetime periods being the least vulnerable to the effects of brain damage, whilst event-specific knowledge is the most vulnerable to loss (Barsalou, 1988; Conway & Rubin, 1993). Lifetime periods and general events represent themes that contextualise and cue the retrieval of event-specific knowledge (Conway, 1992), with self being the main source of these themes.

Several theorists have proposed the existence of a bi-directional relationship between autobiographical memory and self (e.g. Neisser, 1988). Conway and Pleydell-Pearce (2000) developed a model of autobiographical memory construction, based on a dynamic relationship between autobiographical memories and aspects of the self. Within this model the goals of the working self form a subset of working memory control processes that shape cognition and behaviour, in order to operate effectively in the world. The working self is a mental model of the capacities and functions of the system, and its goals are grounded in autobiographical memory. Autobiographical knowledge is encoded through the goal structure of the working self, which also plays a role in constructing specific memories during remembering. The working self and autobiographical knowledge base converge within a self-memory system, to allow autobiographical remembering. When the goals of the working self and autobiographical knowledge are in opposition, this implies a breakdown in the normal functioning of the system. Failures to resolve conflicts within the self-memory system may underlie a range of disorders, including those resulting from neurological damage to the frontal lobes, such as impaired awareness of functioning (Agnew & Morris, 1998).

In summary, autobiographical memory comprises different structural components, with the potential for these to be selectively impaired. Autobiographical memories are not stored as fixed representations, but are reconstructions guided by the self, in which information relevant to the current situation is combined. This theoretical perspective clearly indicates that impairment to autobiographical memory could impact on sense of self, whilst changes in sense of self over time could influence the type of autobiographical memories constructed.

How is autobiographical memory affected in early-stage dementia?

Most studies of autobiographical memory, in healthy older adults, report the distribution across the lifespan discussed earlier (Rubin et al., 1986). However, several empirical studies report profiles of impairment of autobiographical memory in the early-stages of various types of dementia. Findings generally indicate a disproportionate impairment of recent relative to remotely acquired autobiographical memories in association with early-stage Alzheimer's disease, as a result of damage to the hippocampal complex; with a reversal of this temporal gradient in people with semantic dementia, which is underpinned by damage to the neocortex (Addis & Tippett, 2004).

Significant impairment of personal incident memory was found in people with early-stage Alzheimer's disease relative to age-matched controls (Dorrego et al., 1999; Fromholt & Larsen, 1991; Fromholt, Larsen, & Larsen, 1995; Graham & Hodges, 1997; Greene & Hodges, 1996; Greene, Hodges, & Baddeley, 1995; Kopelman, 1989; Piolino et al., 2003b; Sagar, Cohen, Sullivan, Corkin & Growdon, 1988). All of these studies except Fromholt and Larsen (1991), and Fromholt et al (1995) found a temporal gradient, with recent memories being the most impaired. Impairment of personal semantic memory was also found (Graham & Hodges, 1997; Greene & Hodges, 1996; Greene et al, 1995; Kopelman, 1989), but only Kopelman reported a temporal gradient.

In contrast to the temporal gradients observed in association with early-stage Alzheimer's disease, Graham and Hodges (1997), Nestor, Graham, Bozeat, Simons and

Hodges (2002), and Snowden, Griffiths and Neary (1996) found superior recall for recent personal semantic and personal incident memories, compared with those from childhood and early adulthood, in association with early-stage semantic dementia. Piolino, Belliard, Desgranges, Perron, & Eustache (2003a) also found superior recall for personal semantic memories from the recent life period, alongside good recall for personal incident memories from all life periods.

These findings have been considered in relation to the debate surrounding models of long-term memory storage. The standard model of memory consolidation (McClelland, McNaughton, & O'Reilly, 1995; Murre, 1996; Squire & Alvarez, 1995; Teng & Squire, 1999) posits that the hippocampal complex is responsible for memory acquisition and consolidation over time into a hippocampally-independent permanent store within the neocortex. However, the lack of consistent findings of temporally-limited retrograde impairments following bilateral hippocampal lesions, and findings of preserved autobiographical episodic memory across the whole life-span in some patients with advanced semantic dementia (e.g. Westmacott et al., 2001) has lent support to the multiple trace theory (Moscovitch & Nadel, 1998). This suggests that the hippocampal complex is involved in the recovery of autobiographical incidents, regardless of their age. When older memories are retrieved, new hippocampally-mediated traces are created, meaning that older memories are represented by multiple traces. The extent of the impairment back in time depends on the amount of hippocampal damage. Based on this theory, people with semantic dementia should show no effects of time in their autobiographical recall (Nestor et al, 2002).

Unfortunately, a clear interpretation of the findings is complicated by a number of methodological issues, including the heterogeneity of participants, both within and between studies. Participants often differ with respect to the extent of cognitive impairment, stage of disease, and locus and extent of lesion, which may impact on the presence or absence of a significant temporal gradient (Nestor et al., 2002). Whilst some studies control for normal age-related processes, such as changes in living arrangements, independence, marital status, and health (Heidrich, 1998; Whitbourne, 1998), by comparing patient samples with healthy control groups (e.g. Fromholt & Larsen, 1991), other studies compare one patient group with another (e.g. Snowden et al., 1996).

Studies also vary with respect to the tasks employed to study autobiographical memory, including free narratives (e.g. Fromholt & Larsen, 1991); the cue word technique (Galton, 1879; Crovitz & Schiffman, 1974), which involves asking for the first discrete memory that comes to mind in response to random words; and autobiographical fluency, i.e. asking people to recall as many memories as possible within a set time (Dritschel, Williams, Baddeley, & Nimmo-Smith, 1992; Greene et al., 1995). All of these techniques have inherent weaknesses; for example, cue words may or not be relevant to the person's life, whilst the fluency task does not control for the search strategy used.

Whilst the use of non-standardised assessments makes it difficult to compare findings between studies, there is also evidence that different techniques produce different profiles of autobiographical memory. In a sample of healthy older adults, both interviewing and using cue-words elicited the reminiscence bump, but the cue-words produced a higher proportion of recent memories (Fromholt et al., 2003). Different techniques may inherently promote different search strategies; for example, asking people to produce memories in the context of a life narrative may cause a chronological search, whereas asking for responses to cue-words may tap into more accessible recent memories (Fromholt & Larsen, 1991). The development of the Autobiographical Memory Interview (AMI, Kopelman, Wilson, & Baddeley, 1990) has resulted in a well-validated measure that systematically assesses memories from across the life span. However, this measure has also been criticised, as autobiographical memory for a period spanning as much as 30 years between early adulthood and recent life is not assessed, making it difficult to accurately assess temporal gradient (Graham & Hodges, 1997).

There have also been calls for greater consideration to be given to the types of autobiographical episodic memories recalled by participants. Tulving (1985, 2001, 2002) suggested that autonoetic consciousness, i.e. the feeling of mentally travelling back in subjective time and reliving the past, is critical to episodic memory. The presence of this feeling has been assessed using the 'remember/know' paradigm (Gardiner, 1988, 2001; Tulving, 1985), whereby participants are required to report on their experience of remembering. Stimuli are judged as 'remembered' if participants can re-experience a particular associated episode, and 'known' if there is a feeling of familiarity, in the absence of a recollection regarding how the information was originally acquired.

Piolino et al (2003a) used the 'remember/know' paradigm, in conjunction with the AMI, with a patient (AT) with semantic dementia. Whilst AT believed he was 'remembering' to the same extent as a healthy control group, he struggled to justify his remember responses by providing contextual information for any periods other than the previous 5 years. Piolino et al. (2003b) found superior preservation of early memories in a group with Alzheimer's disease, a reversed temporal gradient in a group with semantic dementia, the absence of any clear temporal gradient in a group with frontal-variant fronto-temporal dementia (fv-FTD), and a U-shaped pattern of recall in the control group, when using the AMI. In contrast, their 'remember/know' assessment failed to produce a temporal gradient for episodic memories in the groups with Alzheimer's disease or fv-FTD, both of whom had greater difficulty retrieving strictly episodic memories compared with more generic autobiographical ones. The patients with semantic dementia showed a recency effect for the previous 12 months and the preservation of specific detailed memories from the young adulthood period. The patients with Alzheimer's disease or fv-FTD, but not those with semantic dementia, reported significantly fewer 'remember' responses than the controls.

These findings also demonstrate the differences in recall patterns observed by using different methods. They also suggest that people with semantic dementia may believe they are actively remembering personal episodic memories to a greater extent than do people with Alzheimer's disease or fv-FTD, though they are often unable to justify these judgements beyond the previous 5 years. This indicates that their sense of reliving the past is more subjective than objective (Piolino et al, 2003a,b), perhaps due to a disruption in autonoetic consciousness. In contrast, the patients with Alzheimer's disease or fv-FTD from the Piolino et al., (2003b) study felt that they were reliving their memories to a lesser extent than the controls, indicating greater objectivity with respect to memory functioning.

Autobiographical memory and sense of self in dementia

Although one's self-concept and personality profile tends to remain stable in later-life (Coleman, 1996), impairments to autobiographical memory in early-stage dementia may have implications for sense of self. Some of the theoretical background to self will be discussed briefly before reviewing the evidence that disturbances of autobiographical memory are associated with changes in sense of self.

Self has been described as the unifying context for all experience (Baars, 1997), with the minimal self (Damasio, 1999) being the immediate experience of one's person, and the extended self (Neisser, 1988), or autobiographical self (Damasio, 1999), consisting of elements such as personal knowledge, attitudes, tendencies, beliefs, and narrative memories. In this sense the autobiographical self relates to the self-concept, which represents thoughts and attitudes about the self, and comprises identity, self-esteem, and behaviour (Addis & Tippett, 2004). An integrated longitudinal self, or sense of personhood, requires the alignment of one's current state with enduring semantic knowledge of personal goals, traits, beliefs and values; a process which is thought to be dependent on autonoetic consciousness (Seeley & Miller, 2005).

Seeley and Miller (2005) discuss how impairments in minimal self may be accompanied by insight, and by accommodation of changes by the longitudinal self, with family and carers reporting that the individual is still the person they have always known. However, there are also reports in the literature of perceived changes in aspects of self in association with dementia. Hinton and Levoff (1999) found stories of 'loss of identity' from several caregivers of people with Alzheimer's disease. Similarly, both Gillies and Johnston (2004) and Orona (1990), found that the relatives of people with dementia talked of loss of identity in conjunction with Alzheimer's disease, based on changes in behaviour, abilities, and interpersonal relationships. In relation to individuals with semantic dementia, relatives may perceive changes in the person's identity based on an increasing cognitive and/or behavioural inflexibility (Piolino et al., 2003a; Snowden et al., 1996), as previous self-statements become entrenched and rigid systems of understanding the world in relation to the self (Seeley & Miller, 2005). However, although others may interpret changes in behaviour and abilities as reflecting a change in the person's identity, the subjective view of the person with dementia is seldom considered. Although people with dementia may be aware of these same changes, the interpretations they place on them in terms of changes to sense of self are not clear.

It is likely that many psychological and social factors contribute to expressions of identity in people with a dementia, such as changes in communicative abilities and social interactions (e.g. Harre, 1998; Sabat & Harre, 1992). However, understanding self as a cognitive structure suggests that it would be affected by cognitive impairment due to difficulties with processing, storing, retrieving and applying information (Clare, 2004). Addis and Tippett (2004) examined the impact of impairments in autobiographical memory on aspects of identity, comparing a sample of people with Alzheimer's disease with age-matched controls. The group with Alzheimer's disease were impaired relative to controls with respect to personal semantic and personal incident memory, with significantly poorer recall of recent adulthood and early adulthood personal semantic memories, compared with those from childhood, but no difference in recall for personal incident memories between the different time periods. Relative to the control group, they evidenced significantly less strength of identity; reduced quality of identity; and less positive identity. However, they did not differ from the control group with respect to complexity of identity. Significant positive relationships were found between strength of identity and aspects of autobiographical memory for early adulthood and childhood. This fits with the reminiscence bump hypothesis of Fitzgerald (1988, 1996, 1999), which suggests that memories from this period are closely linked with identity. Significant negative relationships were found between quality, or 'definiteness' of identity and aspects of childhood and early adulthood autobiographical memory. Addis and Tippett (2004) suggest that this may reflect an impairment of abstract summaries of personal knowledge, which provide information about the self in a variety of siutations, with decisions about identity instead being based on a single relevant event, which forces 'all or none' responses.

Conclusions and implications

The most striking finding from this review of the relationship between autobiographical memory and sense of self in early-stage dementia, is the large discrepancy between the importance attributed to this relationship from a theoretical perspective and the limited amount of empirical research conducted. It is unclear why this is so, though it may be due to conceptual and methodological difficulties relating to both autobiographical memory (Brewer, 1986) and self (Byrne, 1996). The lack of consensus with regard to definitions of the constructs to be investigated, and the methods to be utilised, make this a difficult area in which to conduct research. However, even this does not seem to account for the paucity of research, which perhaps better reflects the operation of assumptions regarding the existence of the relationship.

Some studies that have examined changes in sense of self in dementia suggest an underlying impairment in autobiographical memory, without directly investigating whether or not this is the case (e.g. Mills, 1998). Conversely, empirical studies that have examined autobiographical memory impairment may include qualitative background information that implies a possible change in sense of self (e.g. Piolino et al, 2003a; Snowden et al., 1996), but this is not usually investigated further. Reports of changes in identity are often based on carer perceptions (Gillies & Johnston, 2004; Orona, 1990), whereby, identity change is inferred from changes in behaviour, personality, or abilities. The subjective view of the person with dementia is rarely sought.

Understanding the views of the person with dementia, with respect to their identity, has important clinical and research implications. For example, Sabat and Collins (1999) suggest that it is important to consider how self is managed in dementia, as this may impact on manifestations of selfhood and, therefore, how self is measured in studies looking at impairments in dementia. Both Clare (2003) and Pearce, Clare, & Pistrang (2002) suggest that people with dementia differ in terms of their strategies for coping with threats to self. Whilst some attempt to maintain an existing sense of self, perhaps by viewing their difficulties as being restricted to certain areas of ability or activities, others adjust their sense of self to incorporate changes in functioning. The balance between self-protective responses and integrative responses is influenced by partners' coping responses and wider socio-political influences.

Other researchers also suggest the importance of interpersonal relationships for identity maintenance or change in dementia. Gillies and Johnston (2004) suggest that the greatest challenge presented by dementia is holding on to certainty about self, with loss of certainty beginning when the responses of others are inconsistent with one's own view of self. Kitwood (1997) also proposes that dementia mainly affects the adaptive self, which consists of learned ways of responding to others' demands, rather than the experiential self. MacRae (2002) detailed how family caregivers use strategies designed to preserve whatever identity remains. Use of these strategies may be motivated by the desire to protect the person, both from their own evaluations of their situation, and from the evaluations of others; as well as protecting the family from stigmatisation. Strategies can include discrediting potentially embarrassing or stigmatising information, medicalising inappropriate behaviour, fostering independence, and perceiving selectively. Overall, it would seem that identity change, and maintenance, is usually considered in social rather than cognitive terms.

The hypothesised relationship between autobiographical memory and self is utilised in some psychosocial interventions in dementia, with one of the most popular being reminiscence (Woods, Spector, Jones, Orrell, & Davies, 2005). Reminiscence is the process of reviewing autobiographical memories that occurs spontaneously at all ages, especially in older adulthood. When used therapeutically it is thought to confirm and enhance a sense of personal identity, and uses past accomplishments to support a sense of competency (Haight et al., 2003). Despite a paucity of suitable randomised controlled trials, there are promising indications in terms of cognitive, mood, and behavioural outcomes (Woods et al., 2005). Life review is a more structured form of reminiscence that requires people to reminisce over their entire life, and evaluate and reframe troubling events (Haight et al., 2003). A life storybook is created that provides a sense of self and personal history as the disease progresses. This can also be used to communicate the self to others. For both reminiscence and life review, the benefits may be enhanced by the inclusion of the family caregiver (Haight et al., 2003).

An increasing severity of Alzheimer's disease has been associated with an increasing inability to provide an integrated personal history (Fromholt & Larsen, 1991). This suggests that it may be important to conduct life review work in the early stages of Alzheimer's disease, so that life's unfinished business can be resolved before the person is no longer cognitively able to engage with the process (Haight et al., 2003). Schechtman (1994, 1996) highlighted the importance of condensing autobiographical memories from certain life periods into narratives containing the essential features, so that the individual appreciates autobiographical memories as part of an integrated whole. People with semantic dementia may find it more difficult to integrate remote memories into their life narrative, but such work could help people in the early-stages of semantic dementia to retain themes rather than restricted concepts of self.

In conclusion, with respect to the relationship between autobiographical memory and self, it is not possible to generalise from the preliminary findings of one study. The results of Addis and Tippett (2004) require replication, whilst the contribution of other relevant psychological and social factors needs to be examined. Findings of impaired autobiographical memory in dementia are difficult to interpret, as they are partly dependent on the methodology used, whilst identity, which is so uniquely personal, is often inferred from reports by carers. Research in the area would benefit from the standardisation of concepts, definitions and research methodologies. Although dementia has a neurological basis, the literature suggests that the management of many of its symptoms, especially loss of identity, are heavily dependent on social relationships. This may explain why identity change has been viewed predominantly from a social rather than a cognitive perspective within the research literature.

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APPENDIX 1

NOTES FOR CONTRIBUTORS

SECTION THREE – RESEARCH PAPER

CONTENTS

Running head: autobiographical memory, identity, and awareness

Relationships between autobiographical memory, identity, and awareness in early-stage dementia

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Relationships between autobiographical memory, identity, and awareness in early-stage dementia.

Abstract

Impaired awareness of some aspect of functioning, or situation, is an important concept in dementia care, due to its relationship with several clinical variables. The literature suggests that awareness is associated with both self and autobiographical memory. This study examined the relationships of these three variables, within a sample of people with diagnoses of early-stage Alzheimer's disease, vascular dementia, and mixed (Alzheimer's and vascular) dementia. The 30 participants, recruited via a local memory clinic, were each administered the Autobiographical Memory Interview, Tennessee Self-Concept Scale, Second Edition, and Memory Awareness Rating Scale. Partial correlations, controlling for general cognitive ability, revealed that: greater recall of early adulthood personal semantic and incident memories was associated with more definite sense of identity, greater recall of mid-life incidents was associated with less definite identity but greater awareness, and greater awareness was associated with less definite identity. The findings were interpreted with reference to cognitive and biopsychosocial explanations of awareness in dementia. Experiences of memory failure in the earliest stage of the disease may result in the updating of information regarding memory ability in a Personal Data Base. This supports awareness, but reduces certainty regarding identity, as these changes are integrated into sense of self.

Relationships between autobiographical memory, identity, and awareness in early-stage dementia.

INTRODUCTION

Impaired awareness of some aspect of functioning or current situation is a common feature in dementia; and is an important concept in dementia care due to its relationship with several clinical variables. For example, higher levels of awareness seem to be related to higher levels of depression, but better outcomes following cognitive rehabilitation, in the person with dementia (Clare et al., 2004); and lower levels of stress, burden, and depression in caregivers (e.g. De Bettignies et al., 1990). Numerous factors have been identified as influencing awareness, and have been drawn together in a comprehensive biopsychosocial framework (Clare, 2004). This framework highlights the importance of the self as the context within which awareness of one's functioning and situation is experienced and expressed. However, sense of self may alter in early-stage dementia (Orona, 1990), possibly underpinned by changes in autobiographical memory, with which self is theorised to share a bi-directional relationship (Conway & Pleydell-Pearce, 2000). Autobiographical memory is also represented in Morris and Hannesdottir's (2004) model of awareness in Alzheimer's disease, as the necessary store of events containing instances of success or failure on tasks. Thus, the constructs of self and autobiographical memory seem to be closely related, both to each other and to level of awareness. This study represents the first attempt to examine these relationships within a sample of people in the early stages of dementia. The findings will be considered primarily from a cognitive perspective, but also in relation to relevant psychological and social processes, with the aim of increasing our understanding of awareness and the experiential world of the person with dementia.

Clare's (2004) biopsychosocial framework for understanding awareness suggests that the onset of dementia be viewed as a threat to self; with degree of awareness representing the outcome of the interaction of biological, psychological and social processes in response to that threat. Biological changes in dementia underpin difficulties in many areas of cognition, and numerous studies have examined how changes in awareness are associated with cognitive impairments, particularly relating to memory and executive functions (e.g. Mangone et al., 1991; Michon et al., 1994). One aspect of cognition, which Morris and Hannesdottir (2004) propose is important to awareness, and is often impaired in dementia, is autobiographical memory, the store of personal semantic and personal incident memories (Baddeley, 1992). Research has found a disproportionate impairment of recent, relative to remotely acquired, autobiographical memories in association with Alzheimer's disease (Graham & Hodges, 1997; Greene & Hodges, 1996; Greene et al., 1995; Kopelman, 1989), and a reversal of this temporal gradient in people with semantic dementia (Graham & Hodges, 1997; Nestor et al., 2002; Snowden et al., 1996).

Conway and Pleydell-Pearce (2000) posit the existence of a dynamic, bi-directional relationship between autobiographical memory and self, with autobiographical knowledge encoded through the goal structure of the working self, which then plays a role in constructing specific memories during autobiographical remembering. Addis and Tippett (2004) investigated the impact of changes in autobiographical memory on identity, in people with early to moderate stage Alzheimer's disease. Both personal semantic memory and personal incident memory were impaired in those with Alzheimer's disease, relative to a healthy control group. Identity was less definite, contained less dimensions, and was more negative in the group with Alzheimer's disease. Markova (1997) seems to suggest that the highest level of awareness is dependent on an accurate mental representation of the current self, as the individual must not only perceive the presence of a symptom or impairment, but also understand its meaning and the likely impact on self-concept. Thus, autobiographical memory could influence awareness directly, or through its relationship with the self.

Although changes in cognitive functioning may directly underpin changes in aspects of self and awareness, psychological processes influenced by personality, coping style, beliefs, and prior experiences, are also likely to be relevant. For example, the tendency to selectively focus on information that confirms existing self-perceptions, and tailor behaviour in order to produce outcomes that are congruent with these expectations, is a bias that operates with greater strength and persistence when the self-concept is under threat, such as, in relation to the onset of illness (Taylor, 1983; Taylor & Brown, 1988). Clare (2003) suggested that strategies for coping with early-stage Alzheimer's disease fall on a continuum from self-maintaining to self-adjusting responses. Whilst self-maintaining responses reflect a tendency to preserve a prior or existing sense of self, self-adjusting responses reflect a process of adjusting or developing sense of self in line with the effects of the disease. Self-maintaining responses could be perceived by others as manifestations of unawareness, whereas in some cases they might reflect a protective psychological process, such that the assumption of unawareness is inaccurate. Unfortunately, these inaccurate perceptions on the part of significant others are often relevant to diagnosis, intervention, and ongoing care and support. They may undermine the social roles and relationships that provide the evidence needed to support ideas about the self (Cheston & Bender, 1999), and encourage the emergence of a discord between presented and perceived identity, with labels relating to malfunction overriding all other possible identity labels (Gilles & Johnston, 2004).

Although Clare's (2004) framework encourages the consideration of a wide variety of factors when assessing awareness, it does not provide a mechanism by which they may be integrated. However, the recently developed Cognitive Awareness Model (CAM; Morris & Hannesdottir, 2004) may offer a means of understanding the interrelationships between autobiographical memory, identity and awareness. The CAM represents the development of earlier work by Schacter (1989) and Agnew and Morris (1998), and posits that appraisal of abilities is based on the perception of success or failure on cognitive or behavioural tasks. Information regarding the outcome of tasks can be stored in either short-term or long-term episodic memory, but also consolidated in a Personal Data Base (PDB) within semantic memory. The PDB is updated when comparator mechanisms within a central executive system detect a mismatch between the information held in the PDB and current experiences of success or failure. Conscious awareness of failure is generated when a signal is sent to a Metacognitive Awareness System (MAS). Awareness problems can result from an error in updating the PDB, as an impairment of memory prevents the creation of a permanent record relating to evaluation of self-ability. Alternatively, a breakdown in the executive system or comparator mechanisms can prevent the detection of a mismatch between incoming information and the PDB. Finally, a global impairment in the MAS can result in information being detected and stored but not reaching consciousness (Agnew & Morris, 1998).

Within this model autobiographical memory is represented in both episodic memory and in relation to the PDB. Although the PDB is primarily viewed as a store of information relating to ability or impairment, it is influenced by social and cultural inputs, and could also contain memory for more general personal information. In this sense the PDB would be similar to the personal semantic component of autobiographical memory, and would contain self-relevant knowledge necessary for identity. The central executive system and its comparator mechanisms monitor performance, use this information to adjust future behaviour and plans, and also guide the search for relevant information from the PDB. In this sense it is similar to the role played by working self proposed by Conway and Pleydell-Pearce's (2000), with the whole model operating within the general context of the self.

In summary, the literature suggests associations between autobiographical memory, self and awareness. In many cases these relationships are bi-directional, with self being involved in the encoding and reconstruction of autobiographical memories, but also being dependent on autobiographical memory as a store of self-relevant information. Self provides the context within which awareness operates, but accurate appraisal of one's abilities is necessary for the formation of realistic goals, which the self utilises to guide behaviour. This study will investigate the relationships between autobiographical memory, identity as an aspect of self, and awareness, within a single sample of people with early-stage dementia, using an operational definition of awareness as 'an accurate appraisal of everyday memory performance'.

The following specific hypotheses will be investigated:

1. Greater recall of autobiographical memories will be associated with a stronger sense of identity.
2. Greater recall of autobiographical memories will be associated with a greater level of awareness of everyday memory functioning.
3. Greater strength of identity will be associated with a greater level of awareness of everyday memory functioning.

METHOD

Design

This study aimed to explore the relationships between autobiographical memory, identity and awareness of memory functioning, using a correlational design, within a sample of participants with early-stage dementia. Ethical approval was gained from the ethics committee of the School of Psychology, University of Wales Bangor, and the local COREC committee.

Participants

Potential participants were identified by reviewing the clinical records of a memory clinic in North Wales; in consultation with members of staff. Thirty-six individuals were approached, 30 were recruited and provided written consent; giving a response rate of 83%; and 29 fully completed all the assessments. The 30 participants included 6 males and 24 females between the ages of 64 and 91 (M=78.20, SD=6.18). Twenty participants had a diagnosis of Alzheimer's disease (AD), 8 had a diagnosis of mixed (AD and vascular) dementia, and 2 had a diagnosis of vascular dementia, based on the Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition (DSM-IV, American Psychiatric Association, 1994). Twelve participants lived alone in their own home, 16 lived with a spouse, and 2 lived with another family member. Participants were required to be in early stages of the disease process, as defined by a score of 18 and over on the Mini-Mental State Examination (MMSE, Folstein et al., 1975) and/or a Clinical Dementia Rating Scale (CDR; Hughes et al., 1982) score of 0.5 or 1. Only individuals whose clinical notes suggested that they would score within this range were approached; with the MMSE administered to every participant prior to the main measures in order to gain a contemporaneous score. One participant with perceptual difficulties but relatively autonomous daily functioning, having an MMSE score of 16 but rated by another researcher, two months previously, as having a CDR score of 1, was included. MMSE scores ranged from 16 to 29 (M = 22.40, SD = 3.61). Participants were also required to be fluent in English. Individuals with concurrent severe mental health problems were excluded. Each participant was asked whether they would like to have a family member or friend present, and also whether they consented for someone who knew them well to be approached to complete an informant measure. A total of 26 informants became involved with the study: 13 spouses, 1 sister, 8 daughters, 2 sons, and 2 other family members.

Measures

Participants were assessed on standardised measures of autobiographical memory, identity, and awareness of memory functioning.

The Autobiographical Memory Interview (AMI; Kopelman et al., 1990) is a structured interview that assesses personal semantic and personal incident (episodic) memory over three lifetime periods: childhood, early adulthood and recent life. Semantic questions relate to names of schools attended, addresses, names of friends, and other factual information. The maximum possible semantic score for each lifetime period is 21. Incidents are elicited by asking participants to recall a particular event, for example, 'recall an incident occurring while at secondary school', with prompts such as 'involving a teacher', or 'involving a friend' permissible if the person is not initially able to produce a memory. Each incident is scored out of three depending on specificity of time and place, with a maximum possible score of 9 for each period. The measure yields a total semantic memory score and a total incident memory score, along with semantic and incident scores for each of the three lifetime periods.

The AMI has good inter-rater reliability (0.83-0.86), and scores correlated significantly with tests of remote memory (0.28, $p<0.05$-0.68, $p<0.001$) in a sample comprising healthy controls and people with amnesic syndrome. The measure is also able to differentiate between healthy controls and people with amnesic syndrome, with controls obtaining significantly higher scores ($p<0.001$) on both personal semantic and personal incident components. However, the AMI has been criticised for failing to assess the period between early adulthood and recent life, making it difficult to accurately assess temporal gradient of recall (e.g. Graham & Hodges, 1997). Thus, a 'middle to late adulthood' section, developed at the Dementia Services Development Centre, University of Wales Bangor (Jones & Woods, personal communication, 2006), specifically for use with people who have a dementia diagnosis, was included. On this section it was possible to obtain a maximum semantic score of 15, and a maximum incident score of 6. Semantic and incident scores from this newly added period were included in the analyses. An overall semantic score (Total Semantic New) and an overall incident score (Total Incident New) were created by adding the mid-life scores to the original total semantic and incident scores.

As none of the participants were seen in a hospital setting, questions from part 7, which relates to 'present hospital or institution', were re-worded to ask about the home environment and recent visits to hospital, as advised by Kopelman et al. (1990).

The data was used in its raw form for correlational analyses, but was converted to percentages for the purposes of examining the temporal gradient, as the new mid-life section differed from the other sections in its possible maximum score.

Kopelman and colleagues (1990) report that confabulation is not a major issue when administering the AMI, and instructions for administering the scale do not require that memories are checked for accuracy.

The Tennessee Self-Concept Scale: Second Edition (TSCS-II; Fitts & Warren, 1996) consists of 82 statements, for example, 'I am an attractive person'. Statements are rated for self-descriptiveness on the 5-point scale: always false, mostly false, partly false and partly true, mostly true, or always true. Scores can be calculated for: overall self-concept; the components of identity, satisfaction and behaviour; and personal, family, social, moral and physical domains. A short form, comprising the first 20 items, allows for the calculation of an overall self-concept score only. Participants were provided with a printed copy of the response scale, whilst the self-description statements were read aloud. Responses were recorded on the answer sheet by the researcher. Item number 51 was reworded from 'I treat my parents as well as I should' to 'I treat my family as well as I should', since the parents of most participants were deceased.

The TSCS-II scales have good internal consistency (median .80), and test-retest reliability (median .76). TSCS-II total score has been found to correlate with a variety of measures relating to self-concept, including the Self Esteem Inventory (.75; Coopersmith, 1981); and has evidenced discriminant validity when psychiatric patients and offenders have been compared to healthy control participants.

TSCS-II identity score; and TSCS-II response distribution score were used as measures of identity. The response distribution score is a measure of the number of 'always true' and 'always false' responses made, and is a measure of certainty about the way one sees oneself. It will be referred to hereafter as 'definite responses'. Identity correlated highly ($r = .886$, $p<0.001$) with total self-concept score, of which it was a subscale. Thus, to increase power in the analyses, the total self-concept score was not utilised.

The Memory Awareness Rating Scale (MARS; Clare et al, 2002) is a quantitative measure of awareness of memory functioning, based upon the subtests of the Rivermead Behavioural Memory Test-Second Edition (RBMT-II; Wilson, Cockburn & Baddeley, 2003). The subtests of the RBMT-II are analogues of everyday memory tasks, such as remembering a name, a route, and today's date. The MARS items ask about situations that are equivalent to those incorporated in the RBMT-II. For example, the MARS item 'You meet up with a group of people. Some of them you've met before, others you haven't. You need to recognise which ones you've met before' relates to the RBMT-II face recognition task, in which the person is shown 5 faces and later asked to pick those faces out of a larger set, which includes some distractor items. The MARS Memory Functioning Scale (MARS-MFS) compares an individual's ratings of how they think their memory would function in these various everyday situations, with the ratings of an informant, such as a spouse. A positive discrepancy score indicates that the individual rates his or her memory more highly than does the informant; a negative score indicates the opposite. The Memory Performance Scale (MARS-MPS) compares an individual's ratings of their task performance, immediately after encountering the various RBMT-II subtests, with their actual task performance. A positive discrepancy score indicates that the individual's rating of performance exceeds his or her actual performance score; a negative score indicates that the person underestimated his or her performance.

The three component scales of the MARS have good internal consistency (.93-.96). Test-retest reliability was high in the case of the person with dementia (.91-.97) and for the informants (.76-.89). In terms of validity, participant self-ratings correlated significantly with the Memory Symptoms Questionnaire ($p<0.05$; Kapur & Pearson, 1983).

Procedure

Participants were offered the choice of being seen at home or at the University of Wales Bangor; all 30 chose to be seen at home. Each assessment began with the gathering of background information, followed by the measures detailed above. Participants were encouraged to take breaks when necessary, and were offered the option of completing the testing in more than one session. Fourteen individuals chose to complete the assessments during a second visit.

RESULTS

The main analysis focused on examining the relationships between the concepts of autobiographical memory (Autobiographical Memory Interview; AMI), identity (Tennessee Self-Concept Scale - Second Edition; TSCS-II), and awareness (Memory Awareness Rating Scale; MARS). All participants completed the AMI and the participant versions of the MARS. Four people did not have anyone available to them who could complete the informant version of the MARS; thus, the MFS-D score could not be calculated for these individuals. One participant only completed the short form of the TSCS-II, which precluded the calculation of the required subscale scores. There was less than 5% missing data in total; where data was missing, cases were excluded on a pair-wise basis.

Analysis using the one-sample Kolmogorov-Smirnov test indicated that data for all variables were suitable for parametric analysis (z=.420-1.275, p>/=0.05). Statistical analysis was carried out using independent t-tests to explore subgroups differences, Pearson's product-moment correlations to assess the impact of cognitive ability on performance, repeated-measures Analysis of Variance (ANOVA) to assess the temporal gradient of autobiographical memory recall, and partial correlations to investigate relationships between autobiographical memory, identity and awareness.

Overview of scores on the measures of autobiographical memory, identity and awareness.

Table 1 about here

Mean scores on measures of autobiographical memory, identity and awareness are presented in Table 1. In order to verify whether the performance of the sample was comparable to those from other studies, the temporal gradients for both personal semantic and personal incident memory were examined. Figure 1 illustrates the mean percentage recall on both the personal semantic and personal incident aspects of the AMI, for each time period. Repeated-measures ANOVAs revealed significant main effects of time period both for personal semantic memory (F=7.185, $p<0.05$), based on the Greenhouse-Geisser correction, and personal incident memory (F=20.513, $p<0.001$), i.e. there was a significant difference in recall of autobiographical memories across the different lifetime periods. The gradients obtained follow the same pattern as those in other published studies (e,g. Fromholt & Larsen, 1991), i.e. the greatest number of memories recalled related to the earliest time periods, with scores declining in a linear fashion over time. Using the new section appended to the AMI, the number of memories recalled for the mid-life period was slightly lower than for the recent life period.

Figure 1 about here

Influence of Dementia Type.

Despite all but 2 participants having some Alzheimer's component to their diagnosis, it was of interest to ascertain whether the presence of vascular factors impacted on performance. The sample was divided according to type of dementia, with 20 in the Alzheimer's disease group and 10 in the 'other dementia' (mixed and vascular) group, with the scores for each sub-group detailed in Table 2.

Table 2 about here

The groups differed significantly with respect to the AMI recent life period for both semantic and incident memories, with the Alzheimer's group having significantly better recall in both cases. The difference between the two groups with respect to MMSE score almost reached significance; with the Alzheimer's group having a higher mean score, indicating a higher level of cognitive functioning, perhaps underpinning the observed difference between the groups on AMI scores.

Impact of cognitive functioning on obtained scores.

The impact of cognitive ability on participants' scores was explored further by correlating MMSE score, with AMI, TSCS-II definite responses and identity scores, and the two MARS discrepancy scores. It was hypothesised that a higher level of cognitive ability would result in higher scores on the AMI and TSCS-II, and lower discrepancy scores on the MARS.

Table 3 about here

Table 3 shows that MMSE score was significantly correlated with each of the AMI semantic scores, with the exception of the childhood period semantic score. In each case, positive relationships indicated that a higher level of cognitive functioning was associated with greater recall of autobiographical semantic information. The significant negative correlation between MMSE score and MARS-MPS discrepancy score indicated that a higher level of general cognitive functioning was associated with less of a discrepancy between performance on the RBMT-II and self-rating of performance. Once the

Bonferroni correction was applied, in order to control for multiple testing, only the association between MMSE score and recent life semantic score remained significant.

Relationships between Autobiographical Memory, Identity, and Awareness.

Partial correlations were used to investigate the relationships between autobiographical memory, identity and awareness, controlling for general cognitive ability as assessed by MMSE scores.

Relationship between Autobiographical Memory and Identity.

Table 4 about here

Table 4 shows that significant positive partial correlations were obtained between the TSCS-II definite response score and early adulthood semantic and incident memories, even when cognitive ability was controlled, i.e. a more definite sense of identity was associated with greater recall of early adulthood memories. Significant negative relationships were found between memory for mid-life incidents and both aspects of identity, i.e. greater recall of memories from this period was associated with less positive and less definite identity. However, when controlling for multiple testing using a Bonferroni corrected p value of 0.002, these relationships ceased to be significant.

Relationship between Autobiographical Memory and Awareness.

Partial correlations were used to assess the relationships between both the MARS memory functioning discrepancy (MARS-MFS-D) score and MARS memory performance discrepancy (MARS-MPS-D) score, and the various AMI scores, i.e. total semantic and total incident scores, total semantic new and total incident new scores, and the semantic and incident scores for the childhood, early adulthood, mid-life and recent life periods, controlling for current level of cognitive functioning.

Table 5 about here

Table 5 shows that only the negative relationship between MARS-MFS-D and AMI mid-life personal incident memory was significant, and remained so after the Bonferroni correction, i.e. a lower discrepancy between an individual's perception of their memory functioning and the perception of an informant, indicating greater awareness, was associated with greater recall of personal incidents from the mid-life period.

Relationship between Identity and Awareness.

Partial correlations, controlling for general cognitive ability, were used to explore the relationships between identity and awareness. Table 6 presents the significant positive relationships found between the MARS-MFS-D score and both the TSCS-II Identity score,.and TSCS-II definite responses score. This suggests that a greater discrepancy score, and therefore less accurate appraisal of functioning on the part of the individual with dementia, is associated with more positive and more definite sense of identity.

Table 6 about here

DISCUSSION

This study investigated the relationships between autobiographical memory, identity and awareness in people with early-stage dementia. The sample evidenced similar temporal gradients of autobiographical memory to those found in some other studies (e.g. Addis & Tippett, 2004; Kopelman, 1989), with better recall from earlier life periods.

Exploration of the hypothesis that greater recall of autobiographical memories would be associated with a more definite sense of identity, revealed a positive association between better recall of early adulthood semantic and incident memories and a more definite sense of identity, but this was significant prior to Bonferroni corrections for multiple testing only. This is contrary to Addis and Tippett's (2004) finding of a negative relationship between autobiographical fluency for early adulthood memories and definite sense of identity in people with Alzheimer's disease. However, their finding was at odds with their initial expectations, and with the literature, which suggests that autobiographical memories relating to the early adulthood period are encoded during a time of intense self-orientated activity, and underpin the construction of a stable identity and life narrative (Fitzgerald, 1988, 1996, 1999). Thus, it would be expected that impairment of memories from this period would have the greatest negative impact on sense of self and identity.

Findings of the greater recall of mid-life incidents relating to less definite identity are more difficult to interpret, particularly as memories from this period are not usually specifically assessed by the Autobiographical Memory Interview (Kopelman et al., 1990). It could be that memories from this period contain the first instances of failures in memory. Individuals may register the changes in their memory functioning, but in the absence of a diagnosis it may be difficult to attribute meaning (Markova, 1997) creating a sense of uncertainty in the self.

The second hypothesis, i.e. that greater recall of autobiographical memories would be associated with a greater level of awareness of everyday memory functioning, was supported only in terms of the relationship between awareness and mid-life personal incident memories. The lack of any other significant relationships was surprising given the importance placed on autobiographical memory in Morris and Hannesdottir's (2004) model of awareness. Perhaps it is only the circumscribed information regarding ability, extracted in order to update the content of the PDB, that is important, rather than the more general autobiographical memories sampled by the AMI. The mid-life period may differ if it does indeed relate to a time of change in memory functioning. For example, Barsalou, (1988) and Conway (1992) have suggested that autobiographical memories could be viewed primarily as records of success or failure in goal attainment. Thus, the mid-life period may contain a larger proportion of memory failure experiences, relative to earlier periods of life, supporting its relationship with awareness.

The hypothesis that identity would be positively associated with level of awareness of everyday memory functioning was not upheld; in fact the opposite pattern was found, i.e. more positive and more definite identity were significantly associated with less awareness of everyday memory functioning. Interestingly, these relationships were only found in relation to awareness as assessed by the discrepancy between the person's rating of their memory functioning and that of an informant, and not when awareness was assessed in terms of the discrepancy between actual performance on a memory task and ratings of performance. Morris and Hannesdottir's (2004) model suggests that in the absence of recent perceptual input, decisions regarding ability would be made based on the information contained within the PDB. If the PDB is not updated then it will support the belief that functioning is at pre-morbid levels, the individual will not be required to integrate changes into their identity and will, therefore, feel more definite in terms of their identity, but ongoing awareness will be compromised. Another possibility is that any degradation of semantic memory, and thus the PDB, will erode general ideas about identity and force a search of episodic memory for self-relevant information. Identity decisions will then be based on a single relevant incident, but with the information being generalised to the self as a whole, resulting in more all or none responses. The PDB would be compromised leading to impaired awareness, but this would be associated with more definite identity responses (Addis & Tippett, 2004).

Alternatively, the relationship between more definite identity and less awareness could indicate the operation of defensive strategies, designed to protect the self from the psychological distress associated with failure. It is more difficult to utilise these strategies in the face of direct disconfirmation, such as when completing a standardised memory assessment, as with the memory performance aspect of the MARS.

This study provides some preliminary findings with respect to the relationships between autobiographical memory, self, and awareness, but more research is needed in order to better understand the processes involved. Longitudinal studies would be particularly useful, as impairments in awareness have been found to progress over time (Vasterling et al., 1995). The current study also has a number of the limitations, for example, the heterogeneity of participants with respect to age, MMSE score, and diagnosis, with interindividual variability possibly having contributed to a lack of significant results in some cases. There was also a notable gender imbalance, with substantially more females than males having participated. As there was no obvious difference between the genders in terms of those agreeing to participate once approached, this imbalance could reflect the actual ratio of males to females seen by the memory clinic, genuine unsuitability of those males screened in terms of difficulties with physical, psychological or social functioning, or a bias in perceptions regarding the functioning of males relative to females. Unfortunately the data are not available to test these hypotheses, but this is another issue that would need to be addressed in any future studies. The minimum number of participants required to adequately power the study was estimated to be 28 (Cohen, 1992), and although this was exceeded, the corrections needed to control for multiple testing restricted the interpretation of some results. A greater number of participants would, presumably, have contributed to the significance of some of the relationships.

In conclusion, although the results have to be interpreted cautiously, due to a reduction in the number of significant findings following corrections for multiple testing, it seems that the mid-life period is important relative to other periods, in terms of its association with identity and awareness. This stage of life is perhaps the first to contain prodromal incidences of memory failure, occurring before the disease process interferes with the consolidation of new autobiographical episodic memories (Graham & Hodges, 1997; Greene & Hodges, 1996; Greene et al., 1995; Kopelman, 1989). At this stage, the PDB would probably still be updated and would support awareness, but this would require the individual to integrate these changes into their sense of self. This could result in less certainty regarding identity, but allow for sufficient restructuring of the self, in order to maintain the dynamic reconstructive relationship with autobiographical memory (Conway & Pleydell-Pearce, 2000), and the encoding of instances of failure in autobiographical memory. Thus, it seems that models focusing on cognitive neuropsychological factors can aid our understanding of awareness, but they do not offer a comprehensive explanation. Future use of the mid-life section of the Autobiographical Memory Interview may further our understanding of a potentially important, and often overlooked, lifetime period, allowing its contribution to awareness and sense of self to be further explored, and the results to be generalised.

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APPENDIX 1

TABLES AND FIGURE IDENTIFIED IN THE TEXT

		N	Maximum possible score	Mean	SD
AMI Personal Semantic	Total	30	63	45.9	9.0
	New Total	30	78	55.5	11.4
	Childhood	30	21	16.5	4.1
	Early Adulthood	30	21	15.5	3.4
	Mid-Life	30	15	9.6	3.0
	Recent Life	30	21	13.9	4.2
AMI Personal Incident	Total	30	27	11.1	4.8
	New Total	30	33	12.5	5.2
	Childhood	30	9	5.2	2.1
	Early Adulthood	30	9	3.6	2.2
	Mid-Life	30	6	1.4	1.3
	Recent Life	30	9	2.3	1.9
MARS	MFS-D	26	52	14.5	14.8
	MPS-D	30	52	13.1	7.1
TSCS-II	Definite Responses	29	100*	55.9	6.9
	Identity	29	100*	50.2	9.5

Table 1. Performance data relating to autobiographical memory, awareness, and identity (* T-scores).

		Alzheimer's group Mean (SD)		Other dementia group Mean (SD)		t	p
MMSE		23.3	(3.8)	20.6	(2.5)	2.04	.051
AMI Personal	Total	47.0	(9.3)	43.7	(8.6)	.94	.355
Semantic	New Total	57.2	(11.2)	52.0	(11.4)	1.20	.239
	Childhood	15.9	(4.6)	17.7	(2.6)	-1.34	.190
	Early Adulthood	15.9	(3.2)	14.7	(3.8)	.95	.351
	Mid-Life	10.3	(2.7)	8.3	(3.1)	1.77	.088
	Recent Life	15.2	(3.7)	11.4	(4.1)	2.59	.015*
AMI Personal	Total	11.9	(4.9)	9.5	(4.6)	1.30	.206
Incident	New Total	13.5	(5.3)	10.7	(4.7)	1.39	.174
	Childhood	5.4	(2.0)	5.0	(2.4)	.43	.672
	Early Adulthood	3.7	(2.3)	3.3	(2.0)	.47	.646
	Mid-Life	1.6	(1.5)	1.2	(0.8)	.85	.403
	Recent Life	2.9	(1.9)	1.2	(1.5)	2.43	.022*
MARS	MFS-D	14.3	(14.4)	15.0	(16.5)	-.11	.911
	MPS-D	12.3	(7.0)	14.8	(7.2)	-.93	.362
TSCS-II	Definite Responses	56.0	(6.4)	55.7	(8.3)	.10	.920
	Identity	50.6	(8.9)	49.6	(11.3)	.26	.800

Table 2. Comparison of mean scores for the Alzheimer's disease and 'other dementia' groups (*p<.05).

		MMSE score	
		r	p
AMI Personal Semantic	Total	.427	.009**
	New Total	.439	.008**
	Childhood	-.015	.468
	Early Adulthood	.482	.004**
	Mid-Life	.380	.019*
	Recent Life	.549	**.001****
AMI Personal Incident	Total	.140	.230
	New Total	.188	.160
	Childhood	.111	.279
	Early Adulthood	.071	.355
	Mid-Life	.230	.110
	Recent Life	.153	.209
MARS	MFS-D	-.218	.142
	MPS-D	-.353	.028*
TSCS-II	Definite Responses	-.258	.088
	Identity	-.037	.423

Table 3. Correlations between MMSE scores and scores on the autobiographical memory, awareness, and identity measures. (*p<0.05, **p<0.01, correlations in bold are significant once a Bonferroni correction has been applied to the data, p=0.003).

		TSCS Identity		TSCS Definite Responses	
		r	p	r	p
AMI Personal Semantic	Total	.1636	.203	.2537	.096
	New Total	.1473	.227	.2030	.150
	Childhood	.1309	.253	.1759	.185
	Early Adulthood	.1992	.155	.4252	.012*
	Mid-Life	.0599	.381	-.0020	.496
	Recent Life	.0617	.378	.0275	.445
AMI Personal Incident	Total	.0531	.394	.2609	.090
	New Total	-.0449	.410	.1454	.230
	Childhood	.0644	.372	.2037	.149
	Early Adulthood	.0970	.312	.3524	.033*
	Mid-Life	-.3877	.021*	-.4102	.015*
	Recent Life	-.0458	.408	.0392	.421

Table 4. Partial correlations between the autobiographical memory and identity variables, controlling for the effect of general cognitive ability. (*p<0.05, Bonferroni corrected p=0.002).

		MARS-MFS-D		MARS-MPS-D	
		r	p	r	p
AMI Personal Semantic	Total	.0266	.450	-.0633	.372
	New Total	.0229	.457	-.0678	.374
	Childhood	.0646	.380	.0719	.355
	Early Adulthood	.1868	.186	-.0461	.406
	Mid-Life	-.0321	.439	.0608	.377
	Recent Life	-.1710	.207	-.1935	.157
AMI Personal Incident	Total	-.1491	.238	-.1437	.229
	New Total	-.2717	.094	-.1325	.264
	Childhood	-.1485	.239	-.1056	.293
	Early Adulthood	.0158	.470	-.1011	.301
	Mid-Life	-.5603	.002*	-.2049	.143
	Recent Life	-.2414	.123	-.1328	.246

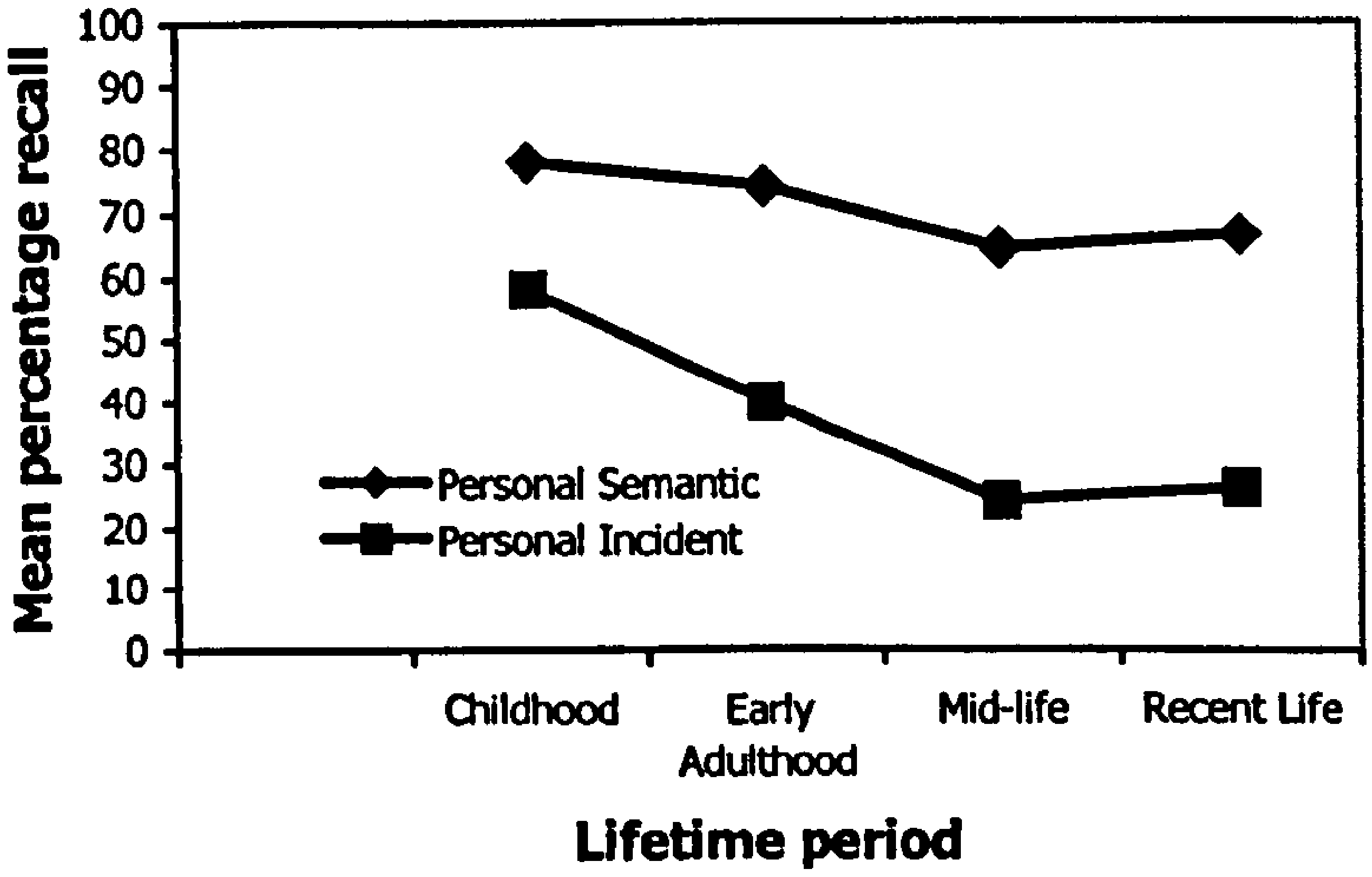
Table 5. Partial correlations between the autobiographical memory and awareness scores, controlling for general cognitive ability. (*p<0.01, Bonferroni corrected p=0.002).

	TSCS Identity		TSCS Definite Responses	
	r	p	r	p
MARS-MFS-D	.4980	.006*	.5503	.002*
MARS-MPS-D	.2196	.131	.1901	.166

Table 6. Partial correlations between identity and awareness variables, controlling for general cognitive ability.

(*$p<0.01$, significant against Bonferroni corrected value of $p=0.006$).

Figure 1. Mean percentage recall of personal semantic and personal incident memories



APPENDIX 2

NOTES FOR CONTRIBUTORS

SECTION FOUR – DISCUSSION PAPER

CONTENTS

Contributions to theory, clinical practice and learning.

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CONTRIBUTIONS TO THEORY, CLINICAL PRACTICE AND LEARNING

The current study represents part of a larger ongoing study into awareness in dementia, with the details of this represented in the ethics application. This paper represents a review and discussion of three key issues relevant to the focus of this thesis. Implications for future research and theory development, and clinical practice will be considered. This will be followed by reflections on the personal experience of conducting the research.

Implications for future research and theory development

Future research will be considered in relation to the personal experience of conducting future research and future research in the wider academic community. Implications will be considered by reflecting on some of the issues encountered during the research process associated with the current study, discussed in roughly chronological order. Implications for theory development will be based on the findings of the current study and issues from the relevant literature.

Recruitment

The initial process of identifying potential participants entailed reviewing memory clinic records, talking with memory clinic staff, and liaising with local researchers who had also conducted studies with this population. Despite the criteria for the study not seeming particularly restrictive, it was difficult to identify participants who both met the criteria and whom clinical staff considered to be appropriate for inclusion. For example, staff suggested that some individuals should not be approached for reasons that included: family conflicts, anxiety or depression on the part of the person, significant hearing or sight problems that would interfere with task performance, difficulties with adjustment to the disease, and general life stressors. Thus, what seemed like a reasonably sizeable pool of potential participants was reduced to a relatively small subset of suitable individuals.

Where possible, details of the study were initially communicated to potential participants via a member of the memory clinic staff who knew the person well, and who could facilitate a visit by the researcher to further explain the study. The remaining people were contacted by telephone and asked if they would allow the researcher to visit and explain the study, so that they could decide whether they wished to take part. Nobody was informed of the study by purely written means. Fortunately, 83% of the people approached consented to take part in the study. Most studies do not report initial response rates so it is difficult to gauge the relative success of the recruitment. However, this higher than anticipated response rate could reflect the time and effort devoted to the earlier stages of participant identification, and the 'personification' of the research during the recruitment process. Although this process was time-consuming, the flow of participants remained constant, which probably reduced the overall time-scale of the assessment stage, and hopefully provided a more satisfying experience for the participants. This highlights the value of careful planning and effort at this early stage, in order to ensure the smooth running of the study.

Sample

The sample was heterogeneous with respect to level of general cognitive functioning as assessed by MMSE score, age, and diagnosis. The impact of general cognitive functioning was controlled for during the analysis. With respect to the impact of age on awareness in dementia, the literature is mixed; with Derouesne et al. (1999) finding that decreased awareness was positively correlated with age, but with Gil et al. (2001) finding no relationship. The inclusion of people with Alzheimer's disease, vascular dementia, and mixed (Alzheimer's disease and vascular) dementia increased the potential pool of participants, but could have impacted on the results by increasing interindividual variability. Much of the research in the dementia literature relates to Alzheimer's disease or semantic dementia, with mixed and vascular diagnoses having received little attention, making it more difficult to interpret the results by reference to the literature. Future studies, based on bigger sample sizes, could investigate the relationships examined in this study in relation to different types of dementia.

Although the screening carried out prior to the actual recruitment was motivated by a desire to avoid causing distress to the most psychologically, physically, or emotionally vulnerable individuals, it is feasible that this process biased the results in some way. All participants were required to be in the early-stages of dementia, but it is possible that those who were included represented a more able subset due to the relative lack of psychosocial difficulties. There doesn't seem to be any easy answer to this dilemma, as ethically and professionally it is important to be guided by the staff who know the person best, and on whose co-operation one is so dependent.

Assessments

The measures utilised were the most well validated and widely used in each case, though some issues arose in relation to two of them that are worth considering. The Autobiographical Memory Interview (AMI, Kopelman, Wilson, Baddeley, 1990) was amended by the addition of a 'mid-life' section to assess the lifetime period covering 40 to 60 years of age. This was developed by a local researcher in response to criticisms (e.g. Graham & Hodges, 1997) that the original version of the AMI did not adequately assess the period between early adulthood and recent life. Significant findings in relation to the mid-life period suggest that this may be an important area to consider in future studies. However, the lack of current knowledge regarding this period made the results of the study difficult to interpret, with no empirical data to support some of the interpretations made of the findings. Future validation of this section will be important, in order to maintain the AMI as a systematic measure for assessing autobiographical memory across the lifespan.

The Tennessee Self-Concept Scale, Second Edition (TSCS-II; Fitts & Warren, 1996) seemed to be the most appropriate measure for use with older adults (Byrne, 1996). However, a change needed to be made to item number 51, from 'I treat my parents as well as I should' to 'I treat my family as well as I should', as most participants' parents were deceased. Although every effort was made to facilitate participants' responses to this measure, such as providing a printed version of the response format, and reading the statements aloud, people reported finding some of the items complicated, especially those that were negative in orientation, for example, 'I do not know how to work well'. In order to ensure that the responses people gave were valid, more time was devoted to this measure than had initially been anticipated. As this scale breaks down into subscales that relate to different domains of self-concept, for example, family, moral, etc., future studies may wish to consider using only the relevant elements. Addis and Tippett (2004) administered just the short form, and although this precludes the calculation of subscale scores for clinical purposes (Fitts & Warren, 1996), their treatment of the scores in this manner may be acceptable for some research purposes.

The amendments made to both assessments mean that the results must be replicated before they can be generalised. Future exploration of mid-life and how it relates to self and awareness may help to elucidate the significance of this lifetime period.

Testing

Participants were variable in their capacity for sustained attention, and whilst some completed the assessments in one session, others required that the assessment process be carried out over two sessions. This again had implications for time management for both the researcher and for the participants. In future it may be prudent to include more of a time contingency when forecasting data collection targets. It may be possible that the number of sessions required represented an important aspect of variability between participants, but this was not explored.

Theory Development

Numerous theories and models were drawn upon in order to interpret the results of the present study. The cognitive model of Morris and Hannesdottir (2004) was used as a basis for understanding the findings relating to mid-life, i.e. greater recall of mid-life incident memories relating to greater awareness but less definite identity. It was hypothesised that this period may represent a prodromal stage in the disease process, during which the PDB was probably still being updated and supporting awareness, but awareness of changes required the individual to update their sense of self, resulting in less certainty regarding identity.

Overall, less awareness was associated with more definite identity. Addis and Tippet (2004) suggest that this type of finding may reflect the degradation of semantic memory, and thus the PDB, which erodes general ideas about identity and forces a search of episodic memory for self-relevant information. Identity decisions are then based on a single relevant incident, but the information is generalised to the self as a whole, resulting in more all or none responses. Therefore, impaired awareness is associated with responses that suggest more definite identity. If this were the case, one might expect an increasingly definite, but restricted and inflexible, sense of self in line with increasing personal semantic memory impairment. It is obvious that much more work needs to be done in this area, in order to fully elucidate the nature of PDB and its relationship to identity and awareness. Longitudinal studies would be beneficial, as predictions could be made and tested over time within the same participants.

Implications for clinical practice

The literature suggests that higher levels of awareness are related to higher levels of depression in the person with dementia, but lower levels of stress, burden, and depression in caregivers (e.g. De Bettignies, Mahurin, & Pirozzolo, 1990). Greater awareness is also related to better outcomes following cognitive rehabilitation (Clare, Wilson, Carter, Roth, & Hodges, 2004). These findings suggest that greater awareness may help the person maintain autonomy and relative independence, both by supporting rehabilitation outcomes and by reducing carer stress, allowing people to perform in this role for longer. However, given that greater awareness seems to relate to greater psychological distress on the part of the person with dementia (De Bettignies et al., 1990) and, according to the findings of the current study, less definite identity, interventions to increase awareness need to consider how to support sense of self and mood.

Pratt, Clare, and Aggarwal (2005) described the development of a user-led model of intervention for people with dementia. This support group provided a social context within which group members could discuss issues and difficulties, ways of coping, and how memory affects planning for future events. The aims were to reduce stress and sense of isolation, and support an integrated sense of self whilst incorporating recent changes in self. Thus the group could help to support awareness and ongoing sense of self, whilst providing the support necessary to assuage difficulties with mood. Such groups are in their relative infancy and require evaluation. Pratt et al. also point out that even though early intervention may prevent future difficulties, the immediate needs of people in the early-stages of dementia may not be defined as 'complex enough' for local health services to justify ongoing input.

Personal and process issues arising from the conduct of the research

This section represents reflections regarding the personal experience of conducting this research, and the lessons learnt. Although some of these issues relate to those discussed in the section on future research and theory development, this section reflects more of the emotional, rather than intellectual, journey.

Time

Reflections relating to the personal experience of conducting this research could not possibly start with anything other than a discussion regarding time issues. The biggest lesson here being to allow much more time than you think you will need, in the hope that this will lessen the stress and sense of frustration. The whole thing looked remarkably straightforward on paper, a timetable containing projections relating to the date of ethical approval being granted, numbers of participants to be recruited, drafts to be written, etc, clearly showed that I had the whole thing well under control. Unfortunately, everything just seemed to take so much longer than anticipated. Ethical approval took longer to secure than anticipated, partly due to the need to translate participant documents into Welsh, a requirement that I should have anticipated. Having to extend the assessments into a second session also slowed down the process, especially as participants were drawn from a large geographical area, necessitating a lot of travelling. The tension engendered by a 'slipping' timetable had to be monitored and contained, so that it did not interfere with the quality of the participants' research experience.

Ethical issues

Although I had worked clinically with people with dementia, I initially felt a level of anxiety with respect to striking the right balance between ensuring that people appreciated what they were consenting to, and not being patronising. Fortunately, this proved not to be an issue as, just as with any person-centred approach, the tailoring of information to the person's requirements felt quite natural. Consent was always revisited on second visits and all participants were happy to continue with the assessments.

As well as these more formal aspects of ethical practice, issues arose during the research that made me feel uneasy. For example, most people spontaneously voiced reasons for agreeing to take part, the most popular being that it might help others in the future. However, some participants, who had minimal social contact in their daily lives, made reference to the fact that taking part in the research fulfilled their desire for human company. Although all reasons for agreeing to participate are equally valid, I did feel uncomfortable that some people's decisions were driven by such a basic human need. However, most participants reported a sense of validation at having their stories listened to.

Why didn't I...

One frustrating aspect of conducting the research was a recurring sense that it could have been approached differently/better/taken into account other variables, etc, etc... This seemed to occur in line with a growing appreciation of the size and scale of the literature. However, through discussions with other researchers, I developed an appreciation that studies have to be manageable, both for the researcher and for the participant. Also, that research proceeds in small steps, despite the scale of the task of building a knowledge base.

The people

Discussing the people involved in the research at this point represents an instance of saving the best until last. Unsurprisingly, this was the most rewarding aspect of conducting the research. The generosity of everyone involved, be they supervisor, memory clinic staff, other researchers, and of course participants, never failed to amaze me, and carried me through when things looked bleak (as they occasionally did).

The willingness of participants to tolerate the experience of failure, alongside opportunities to demonstrate their abilities, was inspirational. Also, their gratitude at being treated as an important source of knowledge was humbling. Although I hope I would never underestimate the devastating impact that a diagnosis of dementia can have on an individual, and those close to them, it seems that how you live, rather than what you live with that is the key, and that is a lesson I can live by everyday.

Conclusion

In conclusion, conducting this research has been a huge learning experience. The original conception of the research seems a long time ago and the process has had its highs and lows. Some aspects of the research went better than anticipated, including the recruitment stage, whereas some aspects were more difficult to manage, such as the time constraints. I will certainly never again underestimate the amount of work required to design, implement and write up a study. Will I conduct research in the future? Perversely, the sense of frustration and stress experienced in association with the current study might provide some motivation to conduct more research in the future, in the hope that next time it will feel better. Though, ultimately, it will be the chance to work with people with a dementia, and better understand their experiential world that will probably lure me back.

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SECTION FIVE – WORD COUNT

Statement of word count

Thesis component		**Word Count**
Title		10
Main Abstract		299
Ethics Application (including introduction)		5023
Literature Review (including abstract & header)		4316
Research Paper (including abstract & header)		5489
Discussion Paper (including header)		2637
	Total:	**17777**
Other components		
References		3038
Appendices:		
Information and consent forms		8899
Measures		4546
R & D application		1751
Tables		630
	Total:	**18864**
	Overall Total:	**36641**