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Self and identity in people with early-stage dementia

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Self and identity in people with early-stage dementia

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**Thesis submitted to the School of Psychology, Bangor
University, in fulfilment of the requirements for the degree
of Doctor of Philosophy**

August 2011



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This thesis is dedicated to

My Grandad

Mr Cecil Caddell

Who is in the end stages of Alzheimer's disease after a 10-year battle



And in memory of

My Nanna

Mrs Moreen Caddell

Whom I never had the chance to meet

My Grandad

Mr Arthur Hamlett

Who had dementia but was too busy having fun to notice

My Nanna

Mrs Annie Hamlett

Who would have been so proud

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Summary

The experience of self and identity in people with dementia has been the subject of much research over recent years, but existing research has a number of limitations, including the lack of a clear theoretical framework and adequate numbers of participants to produce robust evidence. The aim of this thesis was to explore the experience of self and identity in people with early-stage dementia, utilising a mixed method approach, whilst addressing these limitations. Two systematic reviews suggested that a number of relevant research questions had not yet been addressed. These included exploring the profile of identity in people with dementia using a comparison group, and examining the relationships between identity, cognitive abilities, and mood and quality of life. The quantitative aspects of the study involved 50 people in the early stages of dementia, and 50 healthy older people matched on age, gender, and educational background. Results suggested that the experience of identity in people with early-stage dementia is not very different to that of healthy older people. There was also no clear-cut relationship between identity and cognitive and functional abilities, and only a very limited relationship between identity and autobiographical memory functioning. It was possible to significantly predict about a quarter of the variance in mood and quality of life from aspects of identity. The qualitative aspect of the study involved analysing interview data provided by 10 participants, using Interpretative Phenomenological Analysis. The resulting themes demonstrated that participants were in flux, experiencing both continuity and change with respect to their identities, although at present the emphasis was on continuity. The findings are discussed in respect to potential practical implications and directions for future research.

Chapter 1: Introduction

Introduction

The fascination surrounding the nature of self and identity in human beings is widespread among philosophers, psychologists, neuroscientists, and researchers from many other disciplines, as well as non-academics. Studies examining self and identity are growing rapidly in number, with researchers striving to understand how our sense of identity comes into existence, how it can be defined, what function it serves, how it might be represented in the brain, and how it is affected by various pathologies, amongst many other questions. As Klein (in press) points out, there is even a journal devoted to the topic of self and identity (*Self and Identity*), which publishes articles describing a vast number of topics, including self-processes, self-control, self-verification, self-enhancement, self-esteem, self-regulation, self-protection, and self-image. The huge number of topics that fall under the terms of 'self' and 'identity' in current research studies are an indication of the complexities of this subject. The interest in conquering the mystery of the self is certainly not dwindling, and in fact appears to be growing.

Researchers have used a number of approaches to try to answer some of the questions relating to self and identity. These include more traditional techniques, such as using questionnaire measures to record one's beliefs about aspects of oneself (e.g. the Tennessee Self-Concept Scale; Fitts & Warren, 1996) and conducting experimental studies examining processes thought to be related to owning a sense of self, such as self-recognition (a technique which has also been used with non-human species, e.g. Gallup, 1970; Reiss & Marino, 2001), and more recently developed tools, such as employing brain imaging techniques to search for neural correlates of the self (e.g. Northoff & Bermpohl, 2004; Uddin, Iacoboni, Lange, & Keenan, 2007). As in other areas of study, researchers have sometimes found that the best way to understand processes that occur within the brain is to explore what happens in cases where the brain is damaged, or not functioning normally, in addition to studying healthy participants. In the case of exploring aspects of self and identity, information has been gleaned from studies involving people with frontal lobe damage (e.g. Alexander, Stuss & Benson, 1979), right hemisphere pathology (e.g. Fregoli syndrome; Ruff & Volpe, 1981), and people with a disturbed body image (e.g. phantom limb syndrome; Saadah & Melzack, 1994), or a diagnosis of autism (Hobson & Meyer, 2005) or dementia (Seeley & Miller, 2005). Such studies provide a unique

opportunity to observe what happens when self and identity are affected in some way by changes in brain functioning.

Research into self and identity has also taken a developmental perspective, with researchers describing the development of self and identity in children (e.g. Guardo & Bohan, 1971), and reporting changes in self and identity during adolescence (Marcia, 1980; Waterman, 1982), around the time of retirement (Wang, 2007), and especially throughout the aging process (Atchley, 1989; Brandtstadter & Greve, 1994). Although much of the literature concentrates on the changes that occur in healthy aging, over the last 20 years or so research has begun to focus specifically on how self and identity change in older adults who develop dementia. The combination of aging and developing dementia means that people may become less independent (e.g. Baltes, 1988; Bland, 1999; Secker, Hill, Villeneuve, Parkman, 2003), experience losses and stressful life events (e.g. Siegel & Kuykendall, 1990), and are more likely to require formal and informal care and support (e.g. Banerjee, Murray, Foley, Atkins, Schneider, Mann, 2003; Phillips & Diwan, 2003). Aspects relating to both aging and developing dementia are reported to affect a person's sense of self and identity, and have an impact on how these are maintained (e.g. Baltes & Baltes, 1990; Bengtson, Reedy & Gordon, 1985; Coleman, 1999; Fazio, 2008; Troll & Skaff, 1997; Seeley & Miller, 2005). Since a person's identity is believed to foster a sense of well-being (e.g. Berzonsky, 2009; Nurmi, Berzonsky, Tammi, & Kinney, 1997; Thoits, 1983), understanding more about how developing dementia might affect self and identity would be valuable for health professionals and relatives, who aim to support well-being in this population. In light of this, the thesis will focus on how developing dementia affects a person's sense of self and identity, and the implications of this for research and practice.

How can self and identity be defined?

In research, it has proven extremely difficult to reach a consensus regarding the precise definition of self or identity. The Cambridge English Dictionary defines 'self' as:

the set of someone's characteristics, such as personality and ability, which are not physical and make that person different from other people.

Similarly, 'identity' is defined in the Cambridge English Dictionary as:

who a person is, or the qualities of a person or group which make them different from others.

Other dictionaries, such as the Oxford English Dictionary, also provide very similar definitions for the two words, although the definition of self is described partly in terms of consciousness in this dictionary. In a real-world context, the two terms are often used interchangeably, and this will be the case for the purpose of this thesis. However, even within these definitions, there is scope for a variety of interpretations. The terms 'characteristics' and 'qualities' (used above) are vague enough to allow some flexibility and debate regarding what might fall under these categories.

For this reason, psychological research focusing on self or identity has used a wide variety of definitions and theoretical frameworks, which can be problematic in terms of how to integrate and interpret the results of such research. Different fields within psychology attend to self and identity differently. For example, research into self and identity in people with a diagnosis of schizophrenia or autism has included work on body image (e.g. Chapman, Chapman, & Raulin, 1978; Schopler, 1962), which has not been the subject of much scrutiny within dementia studies. Likewise, there has been little work on role-identities in these populations, whereas several studies in dementia have focused upon this aspect of identity (e.g. Cohen-Mansfield, Golander & Arnhem, 2000; Cohen-Mansfield, Parpura-Gill, & Golander, 2006). Thus it is also difficult to integrate and apply findings to other clinical populations.

Within the field of dementia research, some studies or theoretical contributions are based on the assumption that the self is a single entity (e.g. Kontos, 2004), or that it can be assessed by measuring a particular ability (e.g. self-recognition; Biringer, Anderson, & Strubel, 1988) whilst others declare that there are a number of different components that make up the self (e.g. Klein & Gangi, 2010). There are practical and theoretical implications regarding the definition used in such studies, which will be addressed in Chapter 3, along with a discussion regarding the choice of theoretical framework adopted for the purpose of this thesis. Part of the statistical analysis in this study will focus on whether the results support the notion that identity should be viewed as a single entity or as being multi-faceted. This will be discussed in Chapter 5.

Prevalence and types of dementia

Dementia is a neurodegenerative condition that tends to affect older adults, with the prevalence increasing with age, although a small proportion of cases are early onset, i.e. before the age of 65 (Tindall & Manthorpe, 1997). A Welsh Assembly Government document (National dementia vision for Wales, 2011) reported that at least 35 million people worldwide currently have a form of dementia, and it is thought that this will double every 20 years in the future, such that over 115 million people across the world will have dementia by 2050. A recent Department of Health document (Living well with dementia: A national dementia strategy, 2010) reported that about 750,000 people in the UK have a form of dementia, which is projected to rise to over 1 million by 2025. Currently, there are around 37,000 people with dementia living in Wales (Welsh Assembly Government, 2011). Dementia UK, a major report commissioned by the Alzheimer's Society and published in 2007, revealed that Alzheimer's disease accounts for approximately 62% of all cases of dementia, vascular dementia for 17%, and mixed dementia for 10% of dementia diagnoses in the UK. The remaining 11% consists of a number of different types of dementia, including fronto-temporal dementia and dementia with Lewy bodies. The precise figures vary slightly between women and men, with about twice as many women suffering from a type of dementia as men. This thesis will concentrate on people with the three most common types of dementia - Alzheimer's disease, and vascular and mixed dementia.

The different types of dementia are currently diagnosed using either the tenth edition of International Classification of Diseases criteria (ICD-10; World Health Organisation, 1992) or the fourth edition of the Diagnostic and Statistical Manual for Mental Disorders (DSM-IV; American Psychiatric Association, 1994). The criteria central to the diagnosis of the different types of dementia tend to converge across the two diagnostic systems, as described here. Alzheimer's disease is initially characterised by memory deficits, but progresses until many other functions are also affected. The diagnostic criteria vary across different types of dementia, but for Alzheimer's disease a person must be exhibiting memory problems which can be observed through objective memory testing, and at least one other cognitive impairment, such as aphasia (problems with speech, such as word-finding) or executive impairment (for example, difficulties with planning and problem-solving).

These cognitive impairments must result in impairments in daily living, represent a decline from a higher level of functioning, and must not be accounted for by any other neurological disease. The course of Alzheimer's disease is characterised by a gradual onset, and a continuing cognitive decline. The life expectancy of a person with Alzheimer's disease can be unpredictable, and can be influenced by other health problems, but the disease can progress for up to 10 years, or even longer in exceptional cases (e.g. Larson et al., 2004), as the person becomes more and more dependent on care from other people, whether family and friends, or health professionals. However, the average length of survival after diagnosis in the above study was around 5 years.

Symptoms of vascular dementia may be very similar to those of Alzheimer's disease, although vascular dementia tends to have a more sudden onset and a stepwise deterioration (Groves et al., 2000). For a diagnosis of vascular dementia, there must also be focal neurological signs and symptoms, or neuroimaging evidence, of cerebrovascular disease, which are judged to be related to the symptoms. The average length of survival following the onset of vascular dementia has been estimated at around 3-4 years (Fitzpatrick, Kuller, Lopez, Kawas, & Jagust, 2005). Mixed dementia may be diagnosed where patients have both Alzheimer's disease and vascular disease brain pathology, although there are differing opinions regarding how common mixed dementia is. Some researchers believe that many people diagnosed with probable Alzheimer's disease also have cerebrovascular pathology, with one report suggesting that the figure may be nearly 50% (Langa, Foster & Larson, 2004). Prevalence rates also vary massively, with one report noting a range of prevalence rates from 0-55% (Zekry, Hauw, & Gold, 2002) among people with dementia.

This thesis focuses specifically on people in the early stages of dementia, who are still living in their own homes. The Dementia UK report (2007) revealed that older people with more severe dementia are more likely to reside in care homes, as are people with significant behavioural and psychological symptoms of dementia. Most people in the early stages of dementia manage to remain at home, usually with formal, and/or informal support from friends and family. These people therefore tend to be less cognitively impaired and show fewer behavioural and psychological disturbances.

The impact of dementia on society

Dementia places a huge burden on society. The Dementia UK report (2007), estimated that in the UK, 63.5% of people with late-onset dementia (onset of dementia after 65 years of age) live in the community, whilst 36.5% live in care homes. In 2007, the financial cost of dementia to the UK was over £17 billion per year (£25,472 per person with dementia), with family caregivers of people with dementia saving the UK around £6 billion per year. Approximately 16% of carers had given up work or reduced their hours to provide care for the person with dementia. The bulk of the £17 billion cost is accounted for by supported accommodation (41%) and informal care (36%) costs, followed by social services (15%) and NHS costs (8%). It is clear that the effect of dementia on the economy will only increase over the next few decades, potentially to the point of crisis as demands for support increase. Despite this, public funding for dementia lags far behind that of other chronic conditions. The report also recommended that dementia should be made a national priority, with increased funding for dementia research in order to provide evidence-based methods for improving treatment of people with dementia in the future, including psychological therapies. Other recommendations included improving dementia care skills, developing community support, guaranteeing carer support packages, and developing comprehensive dementia care models which would place an emphasis on supporting people with dementia in their own homes.

A further consequence of the fact that many people with dementia live in their own homes is that the health of family carers, who are often the spouses or adult children of the care recipients, may be affected. Research has suggested that carers may be much more prone to depression than non-carers (e.g. Martin, Gilbert, McEwan, & Irons, 2006; Waite, Bebbington, Skelton-Robinson, & Orrell, 2004) and also experience negative effects on the immune system due to the stress associated with caregiving (e.g. Segerstrom & Miller, 2004). Depression in carers is thought to be related to behavioural disturbances in the person with dementia, such as anger or aggression, more than to cognitive difficulties (Covinsky et al., 2003; Donaldson, Tarrier, & Burns, 1997). Such effects may result in increased visits to General Practitioners and an increased use of prescription drugs (George & Gwyther, 1986), which also increase costs associated with caring for people with dementia (McDaid, 2001). Thus, any intervention that might help ameliorate the behavioural symptoms of

dementia could have a beneficial effect on carers' health and also on the economic cost of caring.

Policy on caring for people with dementia

Policy guidelines have evolved from concentrating on the physical needs of the person with dementia to also considering the psychological and social needs of people with dementia and promoting non-pharmacological interventions for symptoms instead of, or as well as, the use of pharmacological interventions. For example, the National Institute for Health and Clinical Excellence guidelines (NICE; Dementia: Supporting people with dementia and their carers in health and social care, 2011) suggest that non-pharmacological therapies should initially be considered for people with dementia whose behaviour is challenging (such as aggression, agitation, wandering, or shouting), or those who are exhibiting signs of depression. Such interventions might include aromatherapy, music-based therapy, animal-assisted therapy, and exercise such as dancing.

Policy writers have also started to recognise the relevance of person-centred care for people with dementia, which was heavily influenced by the work of Kitwood (1997), and have begun to incorporate these principles into policy guidelines. The NICE guidelines (NICE, 2011) state at the beginning of the report that the principles of person-centred care underpin good practice in dementia care. These principles reflect the value and individuality of the person with dementia (including his/her unique personality and life history), the importance of the perspective of the person with dementia, and the importance of relationships and interactions with others. The guidelines also suggest that it might be important to consider a person's individual biography, including religious beliefs and spiritual and cultural identity, and other psychosocial factors when looking for triggers for challenging behaviours that are not related to cognitive abilities. It is also suggested that training programmes for relevant staff members should include information on applying the principles of person-centred care when working with people with dementia and their carers. This includes learning about each person's life story and individuals' preferences and spiritual and cultural identity. A substantial amount of research has focused on aspects of self, identity and personhood in people with dementia, and the implications of this for good quality care and support.

The Department of Health guidelines (Living well with dementia: A national dementia strategy, 2009) make no explicit mention of person-centred care within the guidelines, but there is reference to protecting the individuality of people with dementia, in terms of preferences, sharing life stories and experiences, and developing and maintaining good relationships between people with dementia and relatives, friends, carers, and health professionals. Again, these guidelines encourage the use of non-pharmacological interventions as opposed to prescribing medication for behavioural and psychological symptoms.

Does dementia pose a threat to the self?

Much of the older literature on people with dementia was theoretical or observational, and a common assertion resulting from such work was that people with dementia lost their sense of who they were. Researchers reported that participants experienced a 'loss of self' (Cohen & Eisdorfer, 1986), or an 'unbecoming of self' (Fontana & Smith, 1989), and the 'loss of all those qualities by which we have come to define our humanness' (Robertson, 1991). Many researchers still claim that the self must become lost in people with dementia due to the inevitable decline in cognitive abilities. Much of the relevant literature reports that a sense of identity is based upon either semantic or autobiographical memories, or both, and without intact memory functioning one begins to lose a sense of who one is (e.g. Addis & Tippett, 2004; Conway, 2005; Conway, Singer & Tagini, 2004; Jetten, Haslam, Pugliese, Tonks, & Haslam, 2010; Surr, 2006). Families have spoken of their relative with dementia 'fading away' and 'becoming a shell' as the disease progressed, painting a bleak picture of what it was like to live with dementia. However, some researchers now pay more attention to the perspective of those living with dementia, and the emphasis has changed to involving people with dementia in research (Downs, 1997). Research has begun to challenge the assumption that the self deteriorates in people with dementia (e.g. Kitwood & Bredin, 1992; Sabat & Harre, 1992). Instead of the self and identity of a person with dementia being equated to their level of cognitive functioning, more recently people are being presented as unique individuals with biographies, personalities, preferences, and life circumstances. One of the most influential arguments for the preservation of self in the face of declining cognitive functioning concerns the involvement of other people in maintaining a person's sense of identity. This notion is evident in the social

constructionist model, where a person's social personae can only be created through interactions with others (Fazio & Mitchell, 2009; Li & Orleans, 2002; Sabat, 2002; Sabat & Collins, 1999; Sabat & Harre, 1992; Small, Geldart, Gutman, & Scott, 1998; Tappen, Williams, Fishman & Touhy, 1999). Kitwood (1997) also famously argued for the importance of others in supporting identity in people with dementia, and warned against the effects of malignant social psychology- the undermining of people who have dementia through infantilization, invalidation, stigmatization and objectification, amongst other things. Thus the debate is a complicated one. If one assumes that identity relies upon cognitive abilities then one would expect to see some sort of deterioration in identity as dementia progresses. However, if identity is viewed as being independent of cognitive abilities then the assumption that identity deteriorates as the disease progresses does not have a strong basis. To date, although numerous studies have examined the persistence of self in people with dementia, no study has rigorously examined the relationship of identity with the various cognitive abilities. The body of research into self and identity in people with dementia will be reviewed in Chapter 2 in order to examine how identity has been studied in people with dementia and to draw conclusions regarding the persistence of self and identity in people with dementia. Limitations of current research will also be explored, as well as recommendations for future research. Building on this, Chapter 6 will report the results of a study of the relationships between identity and cognitive and functional abilities.

Supporting the self in people with dementia

A number of researchers have suggested that it might be important to try to preserve the self of people with dementia in order to improve well-being in some way (e.g. Clarke, Hanson & Ross, 2003; George, 1998; Harrison, 1993; Ronch, 1996).

Kitwood's work on person-centred care has been a major influence on the provision of care for people with dementia (Kitwood, 1997). He promoted various aspects that he believed should be incorporated into the care of people with dementia, including attachment, inclusion, comfort, occupation, love, and identity, and suggested that it is possible to maintain personhood through satisfying this combination of needs.

Kitwood particularly emphasized the importance of carers and relatives knowing the individual life story of the person with dementia so that even if the person forgets,

others will maintain his/her identity by filling in the gaps. Whilst this type of work was revolutionary at the time, further efforts have since been made to support identity in people with dementia, although little work has been conducted regarding the relationships between aspects of identity and potentially relevant variables such as mood and well-being. As a result of this, there is little empirical evidence on which to base interventions aiming to support self and identity. Chapter 4 describes a systematic review of interventions that specifically aimed to support identity in people with dementia, and draws conclusions regarding the effectiveness and limitations of the interventions, as well as highlighting areas of potential importance for future research. There is little evidence from which to draw conclusions about exactly who might benefit from such interventions, which to date tend to be conducted with people in the moderate to severe stages of dementia. Chapter 5 will report the results of a study comparing identity in people with early-stage dementia to identity in healthy older people, to determine whether people in the early stages of the disease are experiencing any deterioration in aspects of identity that might benefit from intervention. Chapter 7 will report data pertaining to the relationships between aspects of identity and mood and quality of life, and consider whether the data supports the notion that supporting identity in people with dementia might be beneficial with respect to these variables.

Motivations to examine self and identity in people with dementia: A summary

The above sections highlight some of the limitations of existing research in this field, and point to the need for further research. One of the main challenges in this topic is deciding how best to define self/identity, and it would be beneficial to consider the different approaches that could be taken, and the benefits and drawbacks of such approaches. Without a suitable theoretical framework on which to base future research, the results would be difficult to integrate with those of existing studies, and might thus have little impact or be limited in terms of practical implications. A suitable framework might also make it possible to explore the relationships between different aspects of identity, in order to see whether these are related or could be affected independently of each other.

It would seem important to examine the relationships between aspects of self and identity and other variables, including cognitive abilities and aspects of mood and

well-being. There is much debate over whether declining cognitive abilities in people with dementia are responsible for a deterioration in the self, although to date there is limited evidence to either support or refute this claim. In terms of practical implications it would also be of value to explore whether aspects of self and identity are related to mood and well-being, since this would give an indication of whether it might be useful to design and implement interventions aimed at supporting the self in people with dementia, and what effect this may have.

It would also be useful to explore the subjective experience of developing dementia on the self. Whilst there are some case studies that incorporate views on this topic (e.g. Snyder, 2009), there is a lack of thematic studies that focus very specifically on this issue. A study of this type might highlight further ways in which people with dementia can best be supported, and it would also be of value to explore the emotions and feelings associated with changes in identity, if indeed, these occur. Chapter 8 describes a qualitative study that investigates these issues in a sample of people with early-stage dementia.

Aims of the thesis

The aims of the thesis are to overcome some of the difficulties surrounding existing literature on self and identity in people with dementia, by using a comprehensive theoretical framework that incorporates a number of aspects of identity. The thesis will include systematic reviews of existing studies investigating self and identity in people with dementia, and of interventions that have been used to support identity in people with dementia, in order to identify and address gaps in the literature. These reviews highlight the importance of using a control group to identify differences in identity between healthy older adults and people with dementia, and exploring the relationships between identity, mood and well-being, and identity and cognitive and functional abilities. The thesis will also address the issue of whether there are differences in identity in people with dementia according to gender or marital status, to determine whether all participants in this study can be grouped together for the purposes of statistical analysis. To date, these questions have not been fully addressed by a comprehensive research study. A qualitative study will also be included with the aim of understanding more clearly what effect dementia has on self and identity. Whilst a number of studies have examined the subjective experience of developing

dementia, few have concentrated specifically on this aspect. The findings will be discussed in the light of existing literature, and implications for support and care of people with dementia will be considered.

Research questions

The specific research questions addressed in this thesis are as follows:

1. How do people with dementia score on measures of identity compared to age-matched people without dementia?
2. Are different aspects of self and identity associated in people with dementia and healthy older people, or are they independent of each other?
3. How do the different aspects of self and identity relate to aspects of cognitive and functional abilities?
4. How do the different aspects of self and identity relate to mood and quality of life in people with dementia?
5. What is the subjective experience of the impact of developing dementia on self and identity?

Research Methodology

In order to address all of these research questions, both quantitative and qualitative methods are required. Questions 1-4 require a quantitative approach, such that differences between groups and relationships between variables can be calculated and analysed appropriately, whereas a qualitative approach would be more appropriate for addressing question 5. The work presented here, therefore, is based on a multi-method approach in which both quantitative and qualitative methods have been used to examine self and identity in a sample of individuals with early-stage dementia.

Previous work (Logsdon, Gibbons, McCurry & Terri, 1999; Naylor & Clare, 2008; Ramponi, Barnard, & Nimmo-Smith, 2004) found typical correlation

coefficients to be $\pm .45$ between self-concept and autobiographical memory, depression and quality of life, in controls and those with dementia respectively. A sample size of 30 would have over 80% power for a 5% significance level to show a correlation coefficient of this size to be different from zero. Therefore the minimum sample size for this study was 30 participants. The actual number of participants exceeded this minimum. The quantitative aspects of the study are based on cross-sectional data from 50 people in the early stages of dementia, and question 1 was addressed by making comparisons with data collected from 50 healthy older adults, matched on age, gender and education. Participants were visited 2-5 times in order to administer the measures, which included demographic information, different measures of identity, cognitive and functional abilities, and mood and quality of life. The measures were administered in the same order for each participant, with the identity-related measures completed at the beginning so that ratings of identity would not be affected by any questions on the other measures.

Interpretative Phenomenological Analysis (IPA; Smith, Osborn, & Jarman, 1999) was used to analyse qualitative interview data obtained from a sub-sample of participants, since this method specifically explores lived experience and how people assign meanings in order to make sense of such experiences. IPA is also helpful because it can be used as an exploratory approach to broad research questions, rather than being hypothesis-driven. In this way, IPA attempts to make sense of the participants' worlds through both descriptive and interpretative processes, and provides a thematic account of these experiences. This coincides with the aims of question 5, which is targeting the subjective experiences of people with dementia, and is aiming to explore this topic open-mindedly, without pre-conceptions or pre-defined conceptualisations of identity.

Structure of the thesis

The thesis consists of a number of chapters that are based on journal articles which have been published, submitted for publication, or will be submitted for publication in the future. Material may have been added to, or removed from, the journal articles in order to ensure that adequate information is included in the chapter and also to avoid repetition. However, since some chapters report results from the same group of participants, and often use the same measures of identity, there will be some repetition

in the method sections across empirical chapters. The thesis includes two literature review chapters, one chapter outlining the theoretical framework, four empirical chapters, and a discussion chapter.

Chapter 2 is a systematic literature review that examines the approaches that have been taken to study self and identity in people with dementia, and also evaluates the available evidence in order to draw conclusions about the persistence of self in people with dementia. The review found that it was very difficult to integrate results across studies due to the variety of models and methodologies that have been used to study the self in people with dementia, but drew the general conclusion that most of the evidence pointed to the persistence of self and identity, at least to some degree, throughout the course of dementia. The review also highlighted the limitations of existing studies, including the problematic variation in models and methodologies, but also in terms of significant gaps in the literature. This review has been published in *Clinical Psychology Review* (Caddell & Clare, 2010).

Chapter 3 explores the many models and frameworks that have been used in existing research into the self in people with dementia, and highlights the strengths and limitations of such approaches. A different approach to studying the self in people with dementia is suggested, using an existing systematic and comprehensive framework of the self. This is then used to integrate current research and the advantages and limitations of using this type of approach are discussed. This chapter has been accepted for publication in *Dementia* (Caddell & Clare, in press).

Chapter 4 is a systematic review of interventions that aim to support self and identity in people with dementia. This is included in order to identify the strengths and limitations of current approaches to supporting the self, and also to highlight what type of further evidence would be valuable with respect to supporting the enhancement of existing interventions or the development of new interventions. The review found that most studies were of poor quality, and also highlighted the fact that the development of such interventions is not necessarily based on any evidence regarding the association between aspects of identity and mood and well-being. This chapter has been published in *Aging and Mental Health* (Caddell & Clare, 2011).

Chapter 5 presents the results from the comparison between people in the early stages of dementia and age-matched healthy older people on measures of identity, and also explores the relationships between different aspects of identity in both groups. The results suggested that healthy older adults experienced more identity-related distress and symptoms of anxiety than people with dementia. However, people with dementia scored significantly lower than healthy older people on one measure of identity. The possible reasons for these findings are discussed. In both groups, the different aspects of identity measured were not associated with each other, and the implications of this finding for future research are outlined. This paper has been submitted to *Psychology and Aging*.

Chapter 6 presents findings from a study that focuses on the relationships between aspects of identity and aspects of cognitive and functional abilities. There were a number of associations between these variables, and two out of three aspects of identity could be significantly predicted from models containing various measures of cognitive and functional abilities. The possible reasons for this are discussed, as are the implications for practice. This paper has been submitted to *Aging, Neuropsychology and Cognition*.

Chapter 7 presents results examining the associations between aspects of identity and aspects of mood and quality of life in people with dementia. There were a number of associations between these variables, and all aspects of well-being could be significantly predicted from a model containing various aspects of identity. The possible reasons for these results and the implications for practice are discussed. This paper has been submitted to *International Psychogeriatrics*.

Chapter 8 presents the qualitative study that used Interpretative Phenomenological Analysis to explore participants' perceptions of the impact of dementia on their identity. The four themes emerging from the data represented participants' views on aspects of their current identities, whether they believed that dementia would alter their identities in the future, perceptions of how dementia had affected their lifestyle, and relationships with friends and family. The analysis suggested that for the most part, participants felt that little had changed with respect to their identities as a whole, but most identified features of themselves that were different than they had been prior

to the onset of dementia. The possible interpretations of the data and the clinical implications of the findings are discussed. This chapter has been published in *Dementia* (Caddell & Clare, 2011).

Chapter 9 is the discussion chapter, where the findings are summarised in order of the research questions. The practical implications of the findings will be discussed, followed by methodological considerations relating to this thesis, and possible directions for future research.

Dissemination of findings

The author is aiming to publish all findings of this study in peer-reviewed academic journals, and also to present the results at various relevant conferences both in the United Kingdom and abroad. To date, four chapters have been accepted for publication in academic journals, as detailed below:

Chapter 2:

Caddell, L.S., & Clare, L. (2010). The impact of dementia on self and identity: A systematic review. *Clinical Psychology Review*, 30, 113-126.

Chapter 3:

Caddell, L.S., & Clare, L. (in press). Studying the self in people with dementia: How might we proceed? *Dementia*

Chapter 4:

Caddell, L.S., & Clare, L. (2011). Interventions supporting self and identity in people with dementia: A systematic review. *Aging and Mental Health*. Advance online publication.

Chapter 8:

Caddell, L.S., & Clare, L. (2011). I'm still the same person: The impact of early-stage dementia on identity. *Dementia*, 10(3), 379-398.

Three results chapters have also been submitted for publication, as detailed in the chapter summaries above. In terms of conferences, the following presentations based on data from this thesis have been made to date:

November 2010, Gerontological Society of America, New Orleans:

Paper: The impact of developing dementia on the self

Poster: Relationships between strength of identity, functions of identity and well-being in healthy older people

October 2010, NEURODEM Conference, Cardiff University:

Paper: Self, identity, and well-being in people with dementia

July 2010, British Society of Gerontology, Brunel University:

Paper: Changes in role-identities of people with dementia: Perspectives of people with early-stage dementia and their relatives

Two further abstracts have also been accepted:

November 2011, Gerontological Society of America, Boston:

Symposium paper: Is identity compromised in people in the early stages of dementia?

Poster: Identity and well-being in people with dementia

Conclusion

Self and identity are important aspects to consider when working with people with dementia, due to the implications for how people experience and cope with the illness, as well as for how friends, family and medical professionals treat the person with dementia. Although there have been many studies investigating the persistence of self and identity in people with dementia, there are a number of limitations of these studies, and also numerous gaps in the literature. This thesis aims to address these issues, by using a comprehensive framework of self, and by focusing on pertinent questions relating to self and identity in people with dementia that have not currently been tackled, using a sample size that is sufficiently large to permit robust conclusions.

Chapter 2: The impact of dementia on self and identity: A systematic review

Summary

There is much debate in the literature as to the extent to which self and identity persist in people with dementia. The aim of this systematic review was to examine methods currently used to investigate self and identity in people with dementia, and the resulting evidence as to the persistence of self and identity throughout the course of the disease. Thirty-three studies were reviewed, which showed that many approaches have been taken to studying aspects of self and identity in dementia, including both quantitative and qualitative methods. This appears to be partly due to the differing underlying concepts of self that have been used as a basis for these studies.

Consequently, results obtained from these studies are somewhat disparate, although it is possible to draw some tentative conclusions from the available evidence. Almost all of the studies suggest that there is at least some evidence for persistence of self in both the mild and moderate to severe stages of the illness, although many studies record some degree of deterioration in aspects of self or identity. Further research is required to clarify existing evidence and to address outstanding questions regarding self and identity in dementia.

Caddell, L.S., & Clare, L. (2011). The impact of dementia on self and identity: A systematic review. *Clinical Psychology Review*, 30, 113-126.

Introduction

There is much debate in the literature as to what extent the self persists or diminishes in people with dementia. Some researchers contend that the self remains intact throughout the course of dementia (e.g. Fazio & Mitchell, 2009; Sabat & Collins, 1999), while others insist that the self disintegrates 'until nothing is left' (Davis, 2004). Many others fall in between these two extremes, and suggest that the self is maintained to an extent, although compromised in some way (e.g. Addis & Tippet, 2004; Cohen-Mansfield et al., 2000). This issue is complicated further by the difficulties inherent in defining the self, with researchers using a number of varying definitions of self as a basis for their investigations. The aim of this review is to examine the methods currently used to investigate the self in dementia using these varying definitions, and the resulting evidence as to the persistence of self throughout the course of the disease.

Research into the self in dementia is important for a number of reasons. It is important to understand how people with dementia experience their sense of self because this has implications for how people cope with the illness, how they relate to others, including friends, family, and health professionals, and what types of intervention might be appropriate for them. Several interventions based on aspects of self have already been used with people with dementia, and have presented promising, although preliminary, results (Cohen-Mansfield et al., 2006; Head, Portnoy, & Woods, 1990; Romero & Wenz, 2001).

From a research perspective, the self is very difficult to define, and researchers have based their studies on a wide variety of models and concepts. These models have implications regarding how the self can be measured. Some models and concepts lend themselves to examination or measurement using particular techniques, while ruling out other approaches. One main feature of the methods employed is the distinction between quantitative and qualitative approaches. Some models of self allow a quantitative approach to be applied because self or some aspect of self by that particular definition is measurable by some means. For example, if self or identity is modelled as being dependent on autobiographical memory, it might be possible to measure identity using a questionnaire, and autobiographical memory by examining performance on an objective memory test (Addis & Tippet, 2004; Naylor & Clare, 2008). However, measurement might be more difficult in other areas which are more

suited to a qualitative approach. If self is investigated using the social constructionist model (Sabat & Harre, 1992), it is necessary to examine interactions between the person with dementia and other individuals. In this case, it might be relatively straightforward to find evidence for the presence or persistence of a self, but less easy to infer from this the *extent* to which the self remains. For example, one might conclude that the use of the first person indexical in conversation indicates the presence of a sense of self (e.g. Tappen et al., 1999), but it might be difficult to justify the assertion that the more a person uses the first person indexical, the stronger their sense of self. These are just two examples which illustrate how the model or concept on which a study is based might guide or place restrictions on the methods used to explore or measure this concept, as well as on possible interpretations of results. Since there is no clear or agreed definition of “the self”, this review will focus on the different ways in which researchers have chosen to define and explore the self in people with dementia, rather than restricting the studies included to those fitting a particular model or theory of self or identity.

As a result of the many models used to study self in dementia, a vast range of methodologies has been employed to capture the various aspects of self and to examine whether, and to what extent, these persist. These include quantitative measures, such as questionnaires (e.g., Cohen-Mansfield et al., 2000) and experimental methods such as self-recognition paradigms (e.g. Biringer & Anderson, 1992), in addition to qualitative methods such as interview-based (e.g. Sabat & Harre, 1992) or observational approaches (e.g. Fontana & Smith, 1989). Consequently, there is a wide range of disparate evidence regarding the nature of self in dementia, which makes it difficult to draw any firm conclusions. It would therefore be beneficial to try to integrate the findings from relevant studies in order to derive a clearer picture of the available evidence.

Specifically, the current review has three main aims:

- To explore current approaches to measuring self or components of self in dementia and to illustrate the strengths and limitations of these.
- To consider the current evidence regarding the persistence of self throughout the course of dementia.
- To highlight the implications for future research.

Method

The databases PsycINFO, MEDLINE, CINAHL, ASSIA, and Caredata were searched on 16th March 2009, using the terms “self”, “identity”, “personhood” and “selfhood” with either “Alzheimer’s disease” or “dementia” in the article title. Reference sections of the identified papers were scrutinised for additional relevant studies.

The criteria for the inclusion of studies in the review were:

- Study participants have a diagnosis of dementia (including fronto-temporal dementia, Alzheimer’s disease, vascular dementia, mixed Alzheimer’s disease and vascular dementia, or ‘senile dementia’).
- The study attempts to measure or investigate the presence of self or one or more aspects/components of self, identity, personhood, or selfhood, by directly assessing the person with dementia.
- The article is written in English.

Exclusion criteria were:

- Studies which investigate self/identity/personhood/selfhood only through caregivers’ perspectives.

Results

Thirty-three studies met the inclusion criteria for the review. These are summarized in Table 1. The methodologies used in these studies and the resulting evidence are described below, according to the model of self or identity used in each study, and are grouped into qualitative and quantitative approaches.

Table 1. Studies examining self and identity in dementia

Study	Aim of study	Participants (incl. stage of dementia)	Concept/model of self or identity used	Component of self/identity examined	Methods/Measures	Findings
Social Constructionist Model						
Sabat & Harre (1992)	To explore whether self is lost in AD using a constructionist theory of the nature of self	2 people with AD	Social constructionist theory	The personal self and the multiple social personae	Interviews with the participants were examined for the participants' discursive abilities, sense of professional worth, and other suggestions of a presence of 'self'.	There is support for the theory that the 'self' of personal identity remains intact despite deterioration in cognitive and motor functions. There is also evidence to suggest that 'selves' i.e. the personae that are publicly presented, are also manifested even in the later stages of the disease.
Small et al., (1998)	An investigation of the integrity of self and personae in dementia by examining verbal and non-verbal behaviours of people with dementia and caregivers	17 nursing home residents in a special care unit for people with dementia. Fifteen with dementia diagnoses, mostly AD, and 2 with clinical depression with dementia-like behavioural problems. Also 25 staff; 3 nurses, 18 care aides, 4 support staff	Social constructionist theory (as Sabat & Harre, 1992)	The personal self and the multiple social personae	Interactions were videotaped and transcribed. Markers included first person pronouns, second and third person pronouns, other lexical classes, proper nouns, conflict in interactions, and positioning of personae.	Self and personae in dementia are indexed by both verbal and nonverbal behaviours. Some participants did not use first person pronouns, suggesting compromised self/identity, but showed evidence of retained self in other ways, e.g. defending their rights in conflicts.
Sabat & Collins (1999)	To explore the case of an AD sufferer in order to provide evidence for the existence of indicators of well-being and manifestations of selfhood and thus the existence of intact cognitive functions	Case study; 1 participant with moderate-severe AD	Social constructionist theory	Selfhood; Self 1, the self of personal identity; Self 2, comprised of mental and physical attributes; Self 3, the multiple social personae	The participant was observed at a day centre she attended. Conversations and interactions were transcribed and examined for manifestations of selfhood.	Evidence was found to suggest that Self 1, Self 2, and Self 3 are intact.
Tappen et al., (1999)	To determine whether objective evidence of the persistence of self could be found in people with late-stage AD	23 nursing home residents with middle-late stage AD. Mean MMSE= 10.65	Social constructionist theory (as Sabat & Harre, 1992)	Self in general; not specified further	Use of the first person pronoun 'I', by examining 45 tape-recorded conversations of nursing home residents.	All participants used the first person indexical; most did so frequently. This was interpreted as evidence of persistence of self.
Li & Orleans (2002)	To assess whether a sense of personhood is retained in AD patients residing in a care facility	4 people with AD living in a care facility were the main focus of the study. Many other residents were also involved in the research.	Social constructionist theory	Personhood	Ethnographic; participant observation in the care facility and interviews with family members. Analysed using grounded theory.	Results suggest that a sense of self was preserved in the residents, with their personhood being recognised by families, caregivers, staff, and others.

Sabat (2002)	A social constructionist theory of selfhood is applied to the discourse of a person with AD to explore evidence for an intact self	Case study; 1 participant with probable AD, MMSE= 9	Social constructionist theory (as Sabat & Collins, 1999)	Self 1, the self of personal identity; Self 2, comprised of mental and physical attributes; Self 3, the multiple social personae	Unstructured interviews with the resident were analysed using interpretative biographical methodology in order to examine how relationships, social context, and storytelling might impact on the self.	Evidence was found to suggest that Self 1, Self 2, and Self 3 are intact.
Fazio & Mitchell (2009)	To investigate the persistence of self in people with AD via language (First part of study)	78 adults; 26 without impairments, 26 with mild cognitive impairments, and 26 with moderate cognitive impairments. Those with impairments had been diagnosed with probable AD or a related dementia. In each group, half resided in the community and attended a day centre, and half were in a residential facility.	Social constructionist theory (as Sabat & Collins, 1999)	The personal self and the self of mental and physical attributes (Self 1 and Self 2; Sabat & Collins, 1999)	A semi-structured interview/discussion guide was used to stimulate discussion of self and to elicit the use of pronouns and attributes in all three groups of participants.	Frequency of pronoun and attribute usage decreased across the levels of cognitive impairment. However, when the <i>rate</i> of production was calculated the mean numbers of pronouns and attributes produced per minute were very similar across the three groups. This suggests persistence of self even in moderate dementia.
Self from an interactionist perspective						
Fontana & Smith (1989)	To study the relation between the self as a unique individual and as an entity based on social constructs	Patients with AD at a day-care centre and caregivers at support group meetings	Interactionist perspective	Self	Nonparticipant observation: participants at the day centre were observed, as well as support group meetings and several staff meetings.	The self of AD patients consists mainly of internalised social norms and basic emotional needs. The self 'unbecomes' a self until only emptiness is left. However, caregivers act as agents for the person with AD by imputing to him/her the last remnants of self.
Saunders (1998)	To examine the social construction of identity by dementia patients through the use of accounts of memory loss	17 memory clinic patients; 7 with AD, 4 other cognitive impairment, 2 vascular disease, 1 mixed dementia, 1 alcohol abuse, 1 non-impaired, 1 deferred diagnosis	Interactional sociolinguistic framework	Identity	Interactional discourse analysis and a discursive analysis were used to analyse transcriptions of neuropsychological examinations at a memory clinic.	Participants use 5 types of accounts to discursively construct their identities in social interaction (cognitive, experiential, attention/ability, emotional, comparative). Dementia patients still perform considerable identity construction and maintenance to protect their self-image.

Hubbard et al. (2002)	To explore how people with severe dementia use and interpret non-verbal behaviour	10 participants with dementia from a day centre	Symbolic interactionist perspective	The expression of self through non-verbal behaviour	Researchers used an ethnographic approach; participants were observed in the day centre and asked to interpret particular non-verbal behaviours.	Participants were able to interpret the non-verbal behaviour and actions of others. The authors suggest that this shows that the participants possessed a sense of self.
Embodied Selfhood						
Kontos (2004)	To show that selfhood is maintained through a person's embodied way of 'being-in-the world'	13 participants from a long-term care facility with moderate-severe AD	Embodied selfhood; the theory that the body is a fundamental source of selfhood that does not derive its agency from a cognitive form of knowledge	Selfhood	Ethnographic study; data were presented regarding appearance, social etiquette, caring, dancing, gestural communication.	The participants were aware of their surroundings and engaged with the world. They interacted with coherence, purpose, meaning and improvisation; these are indicative of selfhood. Selfhood is reproduced through our corporeal actions.
Self/identity as narrative						
Mills (1997)	To investigate the relationship between memory and emotion in dementia	8 people (6 male, 2 female) with moderate-severe dementia. All but one lived in the community	Narrative identity as supported by autobiographical memories	Narrative identity	Emotional memories were examined through the use of individual reminiscence work and interviewer counselling skills (mainly Rogerian). The interviews were transcribed and subjected to a grounded theory analysis.	Emotional memories formed fragmented parts of the participants' personal narratives. These stories involving the self gave all informants a sense of narrative identity. This dissolved as the illness progressed and memories gradually faded.
Usita et al. (1998).	Considers the abilities of people with AD to create a narrative compared to those without cognitive impairments	6 people with moderate-severe AD and 6 people residing in the community with no cognitive impairments	Narrative as enabling people to update and define their sense of self	Self	Participants shared their narratives with an interviewer. These were analysed using a classification scheme which considered chronological order, repetition, salient events, and richness of event description.	There were differences between the narratives given by the people with and without AD. However, it is suggested that spared narrative abilities may have allowed those with AD to preserve properties of their selves.

Surr (2006)	To explore whether a socio-biographical theory of self is relevant to people with dementia living in residential care	14 participants with dementia from 4 nursing homes	A socio-biographical theory of self	Self	Unstructured interviews with residents were analysed using interpretative biographical methodology in order to examine how relationships, social context, and storytelling might impact on the self.	Evidence of self was found with respect to relationships with family and other residents, in the adoption of desirable social roles, and in the creation of a life story in interviews. Thus the socio-biographical theory of self is relevant to people with dementia- the quality of interpersonal relationships is important for the preservation of self.
Studies using thematic analyses to examine identity in people with dementia						
Beard (2004)	To examine the impact of being diagnosed with AD on identity	People recently diagnosed with early-stage AD. MMSE 22-26. 3 people interviewed, 10 people observed in a focus group	N/A	Identity	Participant observation including in-depth interviews and focus groups. Transcriptions were analysed using grounded theory.	3 themes emerged; 'defining moments', 'to tell or not to tell' and 'preservation'. Participants implemented strategies to make sense of changes in their identities. In general, identities are being preserved, despite memory loss.
Gillies & Johnston (2004)	To explore the similarities of identity loss experienced by those with cancer and those with dementia, based on findings from two qualitative studies	20 patients with dementia (11 AD, 7 undifferentiated, 2 multi-infarct dementia) 20 patients with cancer	N/A	Identity	Participants were interviewed. Interviews were recorded, transcribed verbatim, and analysed using thematic analyses (Cancer group: grounded theory; Dementia group: comparative analysis).	Both groups experienced a sense of 'role-erosion' as they had to surrender previously held roles. Participants from both groups attempted to reclaim their identity through references to earlier periods in their lives. Self can be preserved and manifested in the face of degenerative illnesses.
Autobiographical memory in relation to self						
Addis & Tippet (2004)	To examine the effect of autobiographical memory loss on aspects of identity (strength, quality, complexity & direction of identity) by comparing AD patients to controls	20 participants with probable AD (17 in own homes, 3 in residential care). Mild-moderate AD, mean MMSE score= 19.85 20 healthy age-matched controls	Autobiographical memory as the basis for identity. Identity as a sub-component of self-concept.	Identity	Autobiographical Memory Interview Identity measured using the 20 Statements Test and the identity component of the Tennessee Self Concept Scale 2 nd Edition	AD patients appear to have a weaker sense of identity than controls, and a more abstract, more vague, and less definite sense of self. Complexity appeared to be less affected. The relative structure of the components of identity was preserved, although the identity

						subscores of the control group were higher overall than in the AD group. Changes in some aspects of autobiographical memory in the AD group influenced changes in some aspects of identity.
Naylor & Clare (2008)	To explore the relationships between autobiographical memory, identity, and awareness of memory functioning	30 participants in the early stages of dementia (20 AD, 8 mixed AD & vascular dementia, 2 vascular dementia). Mean MMSE= 22.40	Social cognitive approach. Identity forms one subcomponent of self.	Identity	Autobiographical Memory Interview Identity measured using the identity component of the Tennessee Self Concept Scale 2 nd Edition	No significant relationship was found between autobiographical memory and identity.
Role-identities as a component of self						
Cohen-Mansfield et al. (2000).	To explore the role-identity of nursing home residents with dementia in order to find out which identities individuals retain in the late stages of dementia	38 participants from two nursing homes with dementia (48% AD, 17% vascular, 7% with Parkinson's, 10% unknown, 17% other) Mean MMSE= 8.7	Concept of self-identity as broad and including roles, identities, attributes, and preferences which an individual attributes to him/herself	Role-identities	Participants, family members, and staff were interviewed using the Self-Identity in Dementia Questionnaire	Many identities were forgotten or reduced in significance, but some are preserved- particularly the familial role. This suggests that some sense of self continues to exist even in the advanced stages of dementia.
Cohen-Mansfield et al. (2006)	To explore the salience of self-identity in people with dementia, as perceived by those with dementia, their families, and by staff caregivers	104 people with dementia; 48 from 6 day centres, and 56 from 2 nursing homes. Average MMSE= 11.16	Self-identity as the identification with roles people assume throughout their lifetimes	Role-identities	Participants, family members, and staff were interviewed using the Self-Identity in Dementia Questionnaire	Role identities persist over the course of dementia, although all identities were significantly reduced in importance from past to present, regardless of the informant group.
Self as self-recognition						
Biringer et al. (1988)	To assess presence and stability of mirror-image recognition in people with dementia	18 women with AD in residential care at GDS level 5, 6, or 7	Self-recognition as reflecting the presence of a well-integrated awareness of self	Self-recognition using a mirror	The mark test- a black mark was left on the forehead of participants, who were then placed in front of a mirror to observe their reaction to the mark. This was repeated three weeks later.	All GDS 5 participants self-recognised in the mirror. Only half at GDS 6 and none at GDS 7 self-recognised in the mirror. Results were fairly stable over the three weeks. It is suggested that the switchover at GDS 6 may represent 'problems differentiating the concept of self'.

Biringer & Anderson (1992)	To assess self-recognition in people with AD using both mirror and video techniques	29 people with probable AD who were residents in long-stay services in university hospitals. 13 were at GDS stage 5 and 16 at stage 6	Self-recognition as an indicator of underlying self-awareness	Self-recognition using a mirror and videotape	Participants were tested for self-recognition using a mirror, and 2-4 weeks later using a video.	25 of the subjects self-recognised in the mirror according to at least one of the three criteria. All the GSD 5 participants self-recognised, whilst 4 GSD 6 participants did not show any evidence of self-recognition. Only 7 subjects showed self-recognition on the video test, 6 of whom were at GDS 5. Therefore signs of self-recognition persist longer in AD patients when tested using a mirror rather than a video, and are more frequent at GDS 5 than GDS 6.
Mendez et al. (1992)	To assess the presence of person-identification disturbances in outpatients with AD	217 outpatients with AD, most of whom were in the mild-moderate stages	N/A	Self-recognition using a mirror	Participants were tested for self-recognition using a mirror.	5 patients misidentified themselves in the mirror (2.3%). All 5 patients exhibited delusions and suspiciousness/paranoia.
Grewel (1994)	To compare the ability of people with moderate and severe dementia to recognise themselves	39 people with AD; 20 moderate AD (mean MMSE= 10.7) 19 severe AD (mean MMSE= 1.9)	N/A (but self-recognition and naming body parts as requiring intact language and visuospatial abilities)	Self-recognition using a mirror	Participant was shown a mirror and asked who the person in the mirror was (1 point if correct).	Mean score for moderate group= 1. Mean score for severe group= 0.2. The correlation between MMSE and test score= .88. Patients with moderate dementia are capable of self-recognition but this capacity is lost as dementia becomes more severe.
Bologna & Camp (1995)	To determine whether an individual with AD who displayed a lack of self-recognition could be shown to display self-recognition through contextual manipulations	Case study; 1 patient with AD who attended an adult day care centre. (MMSE=1, GDS stage 7)	N/A	Self-recognition using a mirror	The participant was seated in front of a mirror and observed for 20 minutes in 5 separate sessions.	The participant showed no spontaneous explicit self-recognition in any of the sessions, even with the interventions in place. However, she used the mirror to comb her hair, suggesting that implicit memory functions remain available.
Bologna & Camp (1997)	To determine whether there is a dissociation between covert and overt self-recognition in people with AD	3 people with AD MMSE; 3,3,2 GDS; 6,6,7	N/A	Self-recognition using a mirror	A mirror was placed in front of each participant to observe immediate response, and to test for overt self-recognition.	None of the participants overtly self-recognised, yet all 3 engaged in primping and conversation with their reflection, suggesting covert self-recognition.

Gross et al. (2004)	Experiment 1 (of 3): to determine the extent to which people with dementia can identify their written names and images of themselves	10 females with AD in a full-time care facility. 3 were moderately impaired, 2 had moderate-severe impairment, and 5 were severely impaired, according to the Cognitive Performance Scale	N/A.	Self-knowledge; written name and self recognition from photographs	Residents had to select their own written names and photographs from a selection featuring other residents.	Participants correctly identified themselves (74% correct) more often than fellow residents, and correctly identified names more often than photographs (90% correct). Thus most patients recognise their own printed name and photographs.
Hehman et al. (2005)	To examine whether an AD patient is able to recognize herself in photographs taken from different decades of her life	Case study; 1 participant with severe AD (MMSE= 7)	N/A	Self-recognition using photographs	The participant was tested on self-recognition using a number of photos of herself spanning 7 decades of her life.	The patient self-recognised only in the photographs taken early in her life, suggesting that self knowledge may have degraded in such a way that she is left with outdated self-knowledge of her appearance.
Fazio & Mitchell (2009)	To investigate the persistence of self in people with AD via visual self-recognition (Second part of study)	78 adults; 26 without impairments, 26 with mild cognitive impairments, and 26 with moderate cognitive impairments. Those with impairments had been diagnosed with probable AD or a related dementia. In each group, half resided in the community and attended a day centre, and half were in a residential facility	Visual self-recognition as an indicator of underlying self-awareness	Self-recognition using photographs	Individual test: each participant had their photograph taken and 3 minutes later were asked who the person in the photo was. Group test: each participant had to identify their own photograph from a group of 5 pictures (their own plus four strangers).	In the individual test condition all those with no impairments or mild impairments self-recognised. 88% of those with moderate impairments also self-recognised. All participants were successful in identifying their own photograph in the group test condition. These results suggest that the self persists in people with dementia.
Self as self-knowledge						
Gil et al. (2001)	A neuropsychological study to investigate how different aspects of self-consciousness, including identity, are affected by AD	27 people with moderate AD (MMSE 10-20), 18 with mild AD (MMSE>20). Mean MMSE= 18.82	Identity as one aspect of self-consciousness, which is viewed as being multi-faceted	Identity	14 questions were posed to participants, of which four related to identity	11.10% of participants gave wrong answers to one or more of the identity questions; most participants were therefore deemed to be conscious of their identity.
Klein et al. (2003)	To examine whether an AD patient has accurate knowledge of her own personality	Case study; 1 participant with severe AD (MMSE= 9)	Self as composed of at least 5 isolable components, including knowledge of one's own personality traits	Self-knowledge of own personality traits	Used the discrepancy between the participant's self-ratings of her own personality traits and relative ratings of the patient's personality traits now and before the onset of dementia.	The participant's ratings were accurate, but reflected her personality before the onset of AD. Self-knowledge is intact, but outdated.

Rankin et al. (2005)	To compare self awareness of personality in patients with fvFTD and AD	12 patients with mild fvFTD 10 patients with mild AD 11 older controls	N/A	Self-knowledge of own personality traits	Participants used the 'Interpersonal Adjectives Scale' to rate their personality. Informants filled out the questionnaire twice, describing the patients' personality now and before the onset of disease (or before retirement/5 years ago for controls).	Patients with FTD were the least accurate at rating their current personality. Although the personality of AD patients had changed according to the relatives, they were as accurate as controls in rating their personality. The FTD patients were accurately describing themselves as they were premorbidly, whereas this was only the case for some of the personality facets in the AD patients.
Ruby et al. (2007)	To investigate social disability and its cerebral correlates in FTD	16 early-stage fvFTD patients each with a close relative 16 matched control couples	N/A	Self-knowledge of own personality traits	Participants asked to rate how well each of 60 adjectives described their own and their relative's personality, now and 10 years ago.	FTD patients and their relatives strongly disagreed about the patients' current personality. However, patients' assessment of their current personality fitted with the relatives' assessment of the patients' personality 10 years ago, suggesting that patients were relying on out-of-date self-knowledge of their personality.
Ruby et al. (2008)	To explore awareness of personality changes in people with AD	14 patients with mild AD and their relatives. 17 elderly controls and their relatives	N/A	Self-knowledge of own personality traits	Patients and relatives rated themselves and each other on a list of 40 adjectives, taking both their own and their relatives' perspective.	The discrepancy between patients' and relatives' views of the patients' personality was greater in people with AD than in controls, but this did not reach significance.

Qualitative Approaches

Qualitative approaches have been widely used to study the self in dementia, and have been applied in the context of several different models of self, including the social constructionist model, interactionist models, embodied selfhood, and self as narrative. The majority of these studies focus on verbal interactions involving people with dementia, but some concentrate on the non-verbal behaviour exhibited by participants. The qualitative methods used and the evidence obtained through these methods will be described below, according to the model of self on which each study was based.

Social constructionist model

The social constructionist model posits that language is of fundamental importance in the creation of social reality, and that the way in which we acquire and use language skills can influence the organisation of thought and experience (see Gergen, 1985). In this way the self can be constructed in and through social interactions with others. The social constructionist model as applied to the study of self in dementia suggests that either two or three types of self exist, depending on whether the earlier (Sabat & Harre, 1992) or the later version of the model is used (Sabat & Collins, 1999). Sabat and Collins argue that Self 1, the self of personal identity, can be displayed through the use of personal pronouns such as “I”, “me”, or “mine”. Self 2, which consists of one’s beliefs and attributes, can also be exhibited through verbal communication, as is the case with Self 3, the multiple social personae which become apparent during interactions with others. This means that all three types of self, according to this model, can be readily demonstrated through the use of speech, which makes techniques that rely on transcriptions of interviews, conversations, or interactions with others ideal for the purpose of searching for evidence of the self. One advantage of this method of exploring self is the ease of accessibility of verbal data which can be used for analysis. However, this method relies on the ability of the participants to use at least some basic speech, which places a restriction on the people with dementia who are able to participate. There is also an issue regarding whether the use of first person pronouns truly reflects a person’s sense of self, or could be verbalised simply out of habit - an issue which Sabat and Harre acknowledge (Sabat & Harre, 1992).

Evidence for Self 1, the self of personal identity, has been examined in six studies by investigating the use of personal pronouns by people with dementia (Fazio & Mitchell, 2009; Sabat, 2002; Sabat & Collins, 1999; Sabat & Harre, 1992; Small et al., 1998; Tappen et al., 1999). These studies have tended to rely on relatively small numbers of participants or on case studies, with the exception of the Fazio and Mitchell study. The majority of these studies suggested that people in the moderate to severe stages of dementia (mostly Alzheimer's disease; AD) commonly used the first person indexical ('I') and also a range of other personal pronouns, which was interpreted as evidence for the self of personal identity (Fazio & Mitchell, 2009; Sabat, 2002; Sabat & Collins, 1999; Sabat & Harre, 1992; Tappen et al., 1999). Small et al. (1998) noted that less than half of their participants used first person pronouns, but these people typically showed evidence of retained self in other ways, such as through defending their rights in conflicts which occurred in the nursing home. Thus overall, it appears that there is strong evidence for the persistence of a self of personal identity according to this model.

Self 2, represented by the person's past and present beliefs and attributes, has been investigated in three studies (Fazio & Mitchell, 2009; Sabat, 2002; Sabat & Collins, 1999). All three studies presented evidence for this type of self, which demonstrated how people in the mild and moderate stages of AD were able to talk about their past attributes with pride, and also reflect on new self attributes which had arisen from the onset of dementia, such as problems with speech and memory.

Several studies also investigated whether there was evidence to suggest the presence of Self 3, the multiple personae, in people with AD (Sabat, 2002; Sabat & Collins, 1999; Sabat & Harre, 1992). All three studies were case studies (one of which included two participants; Sabat & Harre, 1992), and all found evidence of such personae. These personae included those of a scientist, a helper (Sabat & Harre, 1992), a teacher (Sabat & Collins, 1999), an academic, and a social worker (Sabat, 2002), in addition to that of a dementia patient. This evidence, although based only on case studies, is suggestive of the presence of multiple personae through to the severe stages of the disease.

In addition to these studies, Li and Orleans (2002) adopted an ethnographic approach to study the self in AD using the social constructionist model. This study examined self as a whole, rather than looking for evidence of the three types of self proposed above (Sabat & Collins, 1999; Sabat & Harre, 1992), but came to a similar

conclusion. The researchers found that the self was preserved in the residents, and was recognised by relatives of the person with dementia, as well as caregivers and staff at the residential care center where the study was conducted.

Overall, evidence suggests that all three types of self proposed by Sabat & Collins (1999) do indeed persist into the later stages of AD, although the evidence is heavily dependent upon case studies with respect to the presence of Self 3, the multiple personae. Currently there seems to be no evidence to the contrary using this model, although it appears that the aim of these studies was to find and present evidence for the preservation of self, rather than its decline. However, it is difficult to generalise these results to people with dementia who are unable to communicate verbally, or to people with different types of dementia.

Interactionist perspectives on self

Studies founded on interactionist models of self rest on the theory that the self is based on social constructs which are rooted in interactions with others (see Mead, 1934), and tend to involve the analysis of conversations or observations of non-verbal behaviours. One main advantage of observational studies is that people can be observed in their usual environment, over long periods of time, where observations are more likely to be a realistic reflection of their normal behaviour. In addition, such techniques can also be helpful with people in the more severe stages of dementia for whom verbal communication might be difficult. Again, these studies have tended to rely on relatively modest sample sizes, although this is not unusual given the time demands involved in observational studies.

Evidence from this perspective is disparate to some degree, and while this is perhaps partially due to the use of varying interactionist models and methods, it appears to be somewhat inconsistent nevertheless. Saunders (1998) used an interactional sociolinguistic framework (see Gumperz, 1982b) to analyze transcriptions of neuropsychological examinations involving dementia patients and clinicians, and found that people with dementia performed identity construction and maintenance in a variety of ways in social interactions. Patients constructed their identities using cognitive, experiential, attentional, emotional, and comparative accounts during the examination, and were therefore able to protect and maintain their self-image. Hubbard, Cook, Tester, and Downs (2002) took a symbolic interactionist

perspective (see Blumer, 1969) and used an ethnographic approach in order to study non-verbal behaviour in a day centre for people with dementia. They found that non-verbal behaviour was used by people with dementia in a number of ways; participants were able to give meaning to the non-verbal actions of others, use gestures or facial expressions to supplement or replace spoken language, and use physical contact with inanimate objects to convey meaning to themselves (e.g., to remind oneself that something was there). The researchers argued that these behaviours were suggestive of a retained sense of self in people with dementia. Fontana and Smith (1989) also used an interactionist perspective in order to interpret their observations of people with AD at a day-care centre. In contrast to Hubbard et al., they suggested that people with dementia became increasingly incapable of interpreting other people's actions, and lost the ability to define any social situation. In addition, they were only able to respond to situations in a "routinized way", which allowed them to be seen as competent, whilst others attempted to normalise unusual behaviours that they did not understand. The authors concluded that it is friends, relatives and staff members who preserve the self of the person with dementia, by either assuming or pretending that the person is competent, whilst in reality only 'emptiness' remains.

Thus it can be seen that the evidence from these studies is inconsistent to some degree, particularly with respect to the studies conducted by Hubbard et al. (2002) and Fontana and Smith (1989). Both studies focused on participants who attended day centres, yet came to opposite conclusions as to the persistence of self in these people. However, it should be noted that there were several important differences in the methods employed by the two studies. In addition to observing the participants in the day centre, researchers in the Fontana and Smith study also attended support group meetings with caregivers (mostly family members) and staff meetings where alternative perspectives on the participants' behaviour were obtained and used in the analysis. It is possible that these additional perspectives shifted some of the emphasis from the direct observations of the participants to the views of relatives and staff members, which might depart from the actual experiences of the people with dementia. In addition, researchers in the Hubbard et al. study actually participated in activities in the day centre and specifically asked participants to attribute meaning to each other's body language, which might have enabled them to access information that would not have been obtained through nonparticipant observation alone. These

factors could account for at least part of the discrepancy in the conclusions drawn from these two studies.

Embodied selfhood

Only a single study has used this model as a basis for investigating self in people with dementia. Embodied selfhood is based on the premise that selfhood resides in the body itself (see Kontos, 2003), and has been studied using an ethnographic approach which focused on the bodily actions of thirteen people with moderate to severe AD (Kontos, 2004). Again, the main advantage here is that the method allows people in the more severe stages of the illness, who might not be able to communicate well verbally, to participate in the study.

The data presented illustrate how selfhood was observed in the actions of people with dementia in many forms, including behaviours associated with appearance, social etiquette, caring, dancing, and gestural communication. The author concluded that these behaviours indicate that the participants were aware of their surroundings, involved with the world around them, and able to interact with purpose and meaning, all of which were indicative of selfhood.

Self as narrative

Interviews and conversations can be used in studies which examine self or identity through the exploration of personal narratives of people with dementia (Mills, 1997; Surr, 2006; Usita, Hyman, & Herman, 1998). It has been suggested that self depends upon the ability of a person to construct and communicate a narrative (see Bruner, 1987). Participants may be asked to share their narrative with the researcher (Usita et al., 1998), or may be interviewed with reference to various components of their narrative or life story (Mills, 1997; Surr, 2006). This information has been analysed using a variety of methods, including a grounded theory approach (Mills, 1997), a socio-biographical approach (Surr, 2006), or a separate classification scheme developed by the researchers (Usita et al., 1998). The aim of the analysis is to determine how well participants are able to share their narrative, and thus whether they are deemed to possess a narrative identity, or indeed, a sense of self. Once again, the obvious difficulty with this approach is that it restricts the sample to people who

are verbally able. It is possible that even people who are unable to communicate still retain a sense of narrative identity, although they are unable to share it with others.

Three studies have focused on narrative abilities of people with dementia and how these relate to the self (Mills, 1997; Surr, 2006; Usita et al., 1998). All three studies relied on fairly small sample sizes, but reported that most people in the moderate or severe stages of dementia were able, at least to some degree, to construct a narrative which consisted of autobiographical memories, and that this process enabled them to preserve aspects of their self and identity. However, it was acknowledged that these narratives may become compromised as a result of cognitive impairments associated with dementia. This could result in a fragmented narrative (Mills, 1997), which was not necessarily in chronological order, and might also consist of repeated events or the omission of salient events (Usita et al., 1998). It was also recognised that as the illness progressed it became more difficult for people with dementia to share their narratives with others, partly due to the fading of memories (Mills, 1997; Usita et al., 1998). Nevertheless, it was suggested that properties of the self could be preserved even where the narrative was compromised, and it was emphasized that just the process of telling one's life-story could have a beneficial impact on the self (Mills, 1997; Surr, 2006; Usita et al., 1998); a finding which may have practical implications with regard to suitable interventions for people with dementia.

Studies using thematic analyses

Two qualitative studies did not begin by referring explicitly to a particular model or concept of self, but instead used thematic analyses to address self and identity in people with dementia (Beard, 2004; Gillies & Johnston, 2004). This involves analyzing interview data in order to extract common themes which help to describe the subjective experience of self and identity. The advantage of this type of study is that no model or concept is imposed on the data; the researchers form their own theory which is derived from the data they collect. The main drawback is that, once again, this type of analysis is limited to people with sufficient verbal abilities. These studies also used quite modest sample sizes, but this is in keeping with the majority of research that uses such rigorous methods of analysis.

Beard (2004) used a grounded theory approach (see Glaser & Strauss, 1967) to analyse data collected from people with early-stage AD, and found that three themes emerged with respect to the experience of identity construction for people with dementia. These themes (“defining moments”, “to tell or not to tell”, and “preservation”) highlighted the ways in which participants implemented strategies to try to make sense of changes in their identities, and suggested that identities were indeed being preserved, despite memory loss. Gillies and Johnston (2004) used a comparative analysis (see Gillies, 2000) which focused on role identities in people with dementia and in people with cancer. They found that although people with dementia experienced ‘role-erosion’ as they were forced to give up previously held roles, identity could be reclaimed through reference to earlier periods in their lives. Thus, the researchers concluded that self could be preserved and manifested in the face of a degenerative condition such as dementia. These studies both suggest that people with dementia implement strategies to preserve their self and identity despite losses in memory and previously held roles.

Summary

It can be seen that qualitative approaches have been employed in various ways to investigate the self in dementia, and are applicable to several models and concepts of self. The majority of these studies suggest that the self is being preserved in people with dementia, although some studies highlight the losses which may be experienced. These studies are valuable because they provide rich and detailed information regarding the subjective experience of self in dementia, and the thematic accounts in particular are able to describe the actual processes through which people with dementia are attempting to preserve their sense of self. However, most of these studies rely on relatively small sample sizes due to the nature of the methodologies and types of analysis employed, and there are also other questions regarding self and identity in dementia which are difficult to answer using qualitative methods, some of which have been tackled using the quantitative approaches described below.

Quantitative Approaches

Quantitative approaches used in the investigation of self and identity in dementia include experimental techniques and questionnaire measures. These approaches have usually been used to measure a specific component of self, or an ability thought to be related to having a sense of self, rather than to examine self as a unitary construct. Some of these approaches also allow for, or require, collection of information from an informant such as a family member or a member of care staff. The quantitative methods used to study self in dementia and the results obtained through these methods will be described below, according to the component of self or ability that the study is investigating.

Identity as based on autobiographical memory

Several established questionnaires have been used to measure identity in the field of dementia research, such as the Twenty Statements Test (Kuhn & McPartland, 1954) and the Tennessee Self Concept Scale 2nd edition (TSCS-II; Fitts & Warren, 1996). The Twenty Statements Test has been used in one study examining self in dementia (Addis & Tippet, 2004), and requires participants to answer the question “Who am I?” by writing twenty “I am...” statements about themselves. The resulting statements are categorised as attributes, social identities, evaluative descriptions, or physical descriptions, and classified as either specific or abstract, according to a modified coding scheme (Rhee, Uleman, Lee, & Roman, 1995). The Tennessee Self-Concept Scale has been used in two studies to measure identity in people with dementia (Addis & Tippet, 2004; Naylor & Clare, 2008). It consists of 82 statements which are rated on a 5-point scale for self-descriptiveness, from “always false” to “always true”. An overall score can be calculated for self-concept, for three separate components of the self-concept (identity, satisfaction, and behaviour), and for five separate domains (personal, social, family, moral, and physical). Twenty-one of the 82 statements refer specifically to identity, and only these items were used in the studies mentioned below, which have focused on the relationship between autobiographical memory and identity in people with early-stage dementia.

Addis and Tippet (2004) compared people with AD to a control group of healthy older people, and measured autobiographical memory performance with the

Autobiographical Memory Interview (AMI; Kopelman, Wilson, & Baddeley, 1990) and identity with the Twenty Statements Test and the identity component of the Tennessee Self-Concept Scale. They found that people with AD appeared to have a weaker sense of identity, and a more abstract, more vague, and less definite sense of self than the healthy older group, as measured by the Twenty Statements Test. The complexity of identity appeared to be less affected. Responses on the TSCS-II suggested that the direction of identity was not significantly affected, with the relative structure of the components of identity being preserved, although these scores were lower for people with AD than healthy older people. However, the researchers found that of the possible 48 correlations between the four identity variables and twelve measures of autobiographical memory, only six were significant when controlling for MMSE score (with 2.4 expected by chance alone), providing only relatively weak evidence for a relationship between autobiographical memory and identity. They concluded that some components of identity may be directly influenced by impairment in some aspects of autobiographical memory, but emphasized that these findings are only preliminary. Naylor and Clare echoed this finding (2008) in their more recent study of autobiographical memory and identity. The AMI and TSCS-II were also used in this study, yet no significant relationships between autobiographical memory and identity were found. These results are somewhat surprising, particularly in light of the proposed relationship between narrative abilities (which are partially dependent on autobiographical memories) and self or identity described above (Mills, 1997; Surr, 2006; Usita et al., 1998). It may be that the AMI is not tapping into the types of memories that are central to the formation or preservation of a sense of identity, or simply that a larger group of participants is required in order to achieve significant effects on the measures used by Addis and Tippet (2004). It might be beneficial to replicate the study to see whether the six significant correlations constitute a robust result, and if so, to examine more closely why these particular aspects of autobiographical memory and self might be related.

Role identities

The Self-Identity in Dementia Questionnaire (Cohen-Mansfield et al., 2000) was developed to examine role-identities in people with dementia. The questionnaire explores four types of self-identity roles in people with dementia who are residents in

a nursing home: occupational roles, family roles, leisure activities and attributes. There are separate versions for the person with dementia (the resident), their closest family member, and a staff caregiver. The questionnaires ask about how important each of the four roles were to the person with dementia in the past, and how important they are now, on a scale of 1 (not at all) to 5 (very important). In addition, the questionnaire asks for details of these roles, such as what the person's occupation was or what type of leisure activities the person used to enjoy, and enjoys now. The relative and staff versions also ask whether respondents think it would be possible to enhance the participant's sense of identity, and whether they believe that this would be beneficial to the participant. One of the main advantages of this measure is the possibility of gathering information from different sources, which enables the researchers to obtain a more complete picture of how self-identity is exhibited in people with dementia. Another advantage of this measure is the fact that it is relevant to people in the more severe stages of dementia, and concentrates on both verbal and behavioral manifestations of self.

Two studies used the Self-Identity in Dementia Questionnaire to examine role-identities in relatively large samples of people with dementia who were either residents in a nursing home or visitors to a day care centre (Cohen-Mansfield et al., 2000; Cohen-Mansfield et al., 2006). The studies both suggested that all role-identities had either been forgotten or had reduced in significance from past to present, although some were preserved to some extent - particularly the familial role. This was found to be true regardless of the informant group, and was suggestive of the existence of some sense of self, even in the later stages of the illness. The role which appeared to decline in importance the most was the occupational role. One of the studies found a significant correlation between current sense of identity and cognitive performance (as measured by the Mini-Mental State Examination; Folstein, Folstein, & McHugh, 1975), suggesting that an individual's sense of identity deteriorates as the disease progresses (Cohen-Mansfield et al., 2000). Both staff members and relatives felt that it would be possible to increase the sense of identity of the people with dementia residing in nursing homes, and that this would be beneficial to their well-being (Cohen-Mansfield et al., 2000). These studies suggest that although the self does deteriorate in people with dementia, some sense of self or identity remains.

Self-recognition

Studies which have focused on self-recognition as a component of self have adopted more experimental approaches to measurement. These studies have focused specifically on people with AD, and assessed self-recognition using mirrors (Biringer & Anderson, 1992; Biringer et al., 1988; Bologna & Camp, 1995, 1997; Grewal, 1994; Mendez, Martin, Smyth, & Whitehouse, 1992), videotapes (Biringer & Anderson, 1992), and photographs (Fazio & Mitchell, 2009; Gross et al., 2004; Hehman, German, & Klein, 2005). Although these experimental tasks are relatively straightforward to carry out, the main difficulty with this type of study would seem to stem from how one would interpret the results. Researchers have noted many reasons why one might fail to recognize oneself in a mirror or photograph, including a lack of motivation (Biringer et al., 1988), abnormalities in the recognition of body parts and familiar faces (Ajuriaguerra, Strejilevitch, & Tissot, 1963), and an inability to interpret reflected space (Breen, Caine, & Coltheart, 2001). For this reason, it appears troublesome to equate a lack of self-recognition with a lack of sense of self.

Results of all of the studies involving mirrors suggest that some people with AD are unable to identify themselves in the mirror (Biringer & Anderson, 1992; Biringer et al., 1988; Bologna & Camp, 1995, 1997; Grewal, 1994; Mendez et al., 1992). Some of these studies involved participants who were at different stages of their illness, and these studies suggest that people in the more severe stages of dementia are less likely to self-recognize in the mirror than people in the earlier stages (Biringer & Anderson, 1992; Biringer et al., 1988; Grewal, 1994). Biringer et al., (1988) concluded that this loss of ability in the more severe stages of dementia may represent 'problems differentiating the concept of self,' while Mendez et al., (1992) suggested that misidentifications might be associated with delusions and paranoia.

Biringer and Anderson (1992) also used videotapes in their study, and found that fewer participants were able to self-recognize on the videotape than when using the mirror. Again, their results suggested that those who have more severe impairments are less likely to self-recognize.

Three studies examined self-recognition using photographs (Fazio & Mitchell, 2009; Gross et al., 2004; Hehman et al., 2005). Gross et al. found that when care home residents were asked to pick out the photograph of themselves from a set of three photographs, two of which featured other residents at the home, they were

correct on 70% of trials. A more recent study (Fazio & Mitchell, 2009) found that all participants with mild or moderate impairments were able to correctly identify the photograph of themselves when faced with a selection of five photographs. However, the distractor photographs in this study featured complete strangers, rather than acquaintances or fellow residents, which may have made the task of self-recognition easier for the participants in this study. This study also showed that when presented with an instant photograph of themselves taken just a few minutes earlier, all people with mild impairments and 88% of people with moderate impairments were able to identify the person in the photograph as themselves. The case study reported by Hehman et al. found that the participant was only able to self-recognize in photographs which were taken early in her life, and that her recognition for pictures taken from age 40 onwards was much poorer. The researchers suggest that self-knowledge regarding appearance may decay in such a way that only outdated knowledge is retained in memory. It would be valuable to replicate this study with a larger sample size in order to see whether this temporal gradient in self-recognition is common to other people with dementia.

In sum, evidence suggests that people with AD often do show difficulties with self-recognition. This seems to be the case particularly in the later stages of the illness, although robust evidence for this is only currently present in studies involving mirror self-recognition. It also appears that people with AD are more likely to self-recognize using photographs rather than mirrors, although the reasons for this remain unclear. As discussed earlier, it is probably unwise to assume that a lack of self-recognition necessarily equates to a lack of self, given the range of possible explanations for this phenomenon. Also, as these studies have only focused on people with AD, it is unclear whether these findings would generalise to people with different types of dementia.

Self-knowledge

Several studies have focused on self-knowledge as a component of self, including personal knowledge such as one's name and past job, and more frequently, knowledge of one's own personality traits. Such studies have suggested that knowledge of one's self or identity might constitute an isolable component of self (Klein, Cosmides, & Costabile, 2003) or one aspect of 'self-consciousness' (Gil et al., 2001).

One study used four items from a specially developed questionnaire to measure identity in people with mild and moderate AD (Gil et al., 2001). These questions concerned the participant's name, past job, partner's name, and mother's first name, with almost 90% of participants answering all four questions correctly. Based on this, the researchers concluded that the majority of participants were conscious of their identity, although it seems difficult to justify how a complex construct such as identity could be assessed using such a limited range of items.

Studies based on the concept of self-knowledge of personality as a component of self have used discrepancy scores in order to measure a person's knowledge of his/her own personality traits (Klein et al., 2003; Rankin, Baldwin, Pace-Savitsky, Kramer, & Miller, 2005; Ruby, Schmidt, Hogge, D'Argembeau, Collette, & Salmon, 2007; Ruby et al., 2009). Typically, the person with dementia is provided with a list of adjectives and asked to rate his/her own (current) personality traits on this, whilst a family member is also asked to rate the person's current personality traits on a parallel list. In three of the studies (Klein et al., 2003; Rankin et al., 2005; Ruby et al., 2007), relatives were also asked to rate the person's personality traits as they were before onset of dementia. A discrepancy score between the person's self-ratings of current personality traits and the relative's ratings of that person's current personality traits is then calculated, in order to ascertain the person's level of self-knowledge regarding current personality. The lower the discrepancy score between the ratings, the more accurate the person's self-knowledge is said to be. The discrepancy score between the person's ratings of current personality and the relative's ratings of that person's personality before the onset of dementia is used to assess whether the person is rating his/her personality as it used to be, as opposed to how it is currently. If the discrepancy score between these two ratings is low, this might suggest that the person's knowledge regarding his/her own personality traits has not been updated since the onset of dementia, and is reflecting an outdated knowledge of self. This approach is relatively quick and easy to use, and has the advantage of not only checking how accurate a person's current self-knowledge is, but also whether inaccurate current self-knowledge might be due to an outdated sense of self. The main disadvantage of this type of measure is its reliance on relatives to accurately rate the person's personality traits. Klein et al. (2003) are the only researchers to address this issue, by examining the accuracy of the informants in rating other individuals. This was achieved by examining the agreement between these and other informants'

ratings of different individuals who were known to all of the informants. At least in this study, the relative and staff caregiver rating the participant's personality appeared to be relatively accurate in rating the personalities of other people in general.

Results using these methods have been obtained for people with fronto-temporal dementia (FTD) and Alzheimer's disease (AD). Results for people with early-stage FTD suggest that this group of people tend to be quite inaccurate in rating their current personalities; however, the ratings given by people with FTD for their current personality closely match the ratings given by relatives regarding the person's pre-morbid personality (Rankin et al., 2005; Ruby et al., 2007). This suggests that people with early-stage FTD may rely on outdated knowledge of their personality when asked to report their traits. Results for people with AD are less conclusive. One case study found that a person with severe AD was rating her personality as it had been before the onset of dementia, rather than how it was currently, as appears to be the case for people with FTD (Klein et al., 2003). However, larger studies with people with early-stage AD have found that they tend to be more accurate at rating their current personality traits. One study found that people with early-stage AD were as accurate at rating their personality as a control group (Rankin et al., 2005), whilst another study reported that although a greater discrepancy between self and informant ratings was found for people with early-stage AD compared to a control group, this difference was not significant (Ruby et al., 2008). Taken together, these results suggest that people with early-stage FTD appear more likely than people with early-stage AD to have inaccurate, or outdated, knowledge of their personality traits, but currently it is not known whether this finding applies to people who are in the later stages of the illness. In addition, it is difficult to equate a loss of self-knowledge to a loss of self, due to the number of factors which might influence a person's ability to accurately judge their personality traits, such as impairments in memory or judgment, a general or domain-specific lack of awareness, or processing or comprehension difficulties.

Summary

The quantitative studies described above clearly target quite different components of the self, or abilities which are purported to be related to the self. The sample sizes for these studies range from single case studies to large sample sizes of over 200

participants (Mendez et al., 1992). It is therefore difficult to integrate the results from all of these studies in order to come to any conclusion about how the self as a whole is affected by dementia, but the evidence seems to suggest that some of these components or abilities do deteriorate to some extent as the disease progresses. These quantitative studies provide a valuable insight into how aspects of the self might be affected in various ways by the disease process as it progresses.

Discussion

The aim of this review was to examine the methods used to study self in dementia, the resulting evidence regarding the persistence of self throughout the course of the disease, and the implications for future research. It can be seen that both qualitative and quantitative methods have been used to study self in dementia, and that even within these two domains, methodologies have varied considerably. Consequently, results obtained from these studies are rather disparate, but it is possible to draw some tentative conclusions from the available evidence. Issues relating to the methods used and results obtained from these studies will be discussed below, and will be followed by a consideration of possible directions for future research in this field, given the limitations of the current studies.

The variation in methods used to study self in dementia is partly a reflection of the variety of models on which studies have been based. Qualitative methods have been used mainly to focus on evidence for the self which is apparent in interactions involving the person with dementia. These types of study are beneficial because they provide an in-depth view of how the self is manifested and experienced in people with dementia, which can be demonstrated using the participants' own words. One limitation of such studies is that they often neglect to emphasize the impact that changes in the brain and cognition may have on the self. In addition, the majority of these studies focus only on people with dementia who have intact verbal abilities, which is likely to rule out many people in the severe stages of the illness and therefore again limits the generalisability of results. It is also worth noting that these studies tend to search for evidence which supports the persistence of self, rather than a deterioration in self, which could reflect pre-existing beliefs of the researchers regarding the effect of dementia on the self.

Quantitative studies used to explore self in dementia are quite disparate, and include experimental studies in addition to questionnaire measures. These studies are quite specific about which aspect of self they are measuring, and are less likely to try to capture ‘the self’ as a unitary construct. An obvious advantage to some of these techniques (particularly the questionnaire measures) is their ability to capture evidence which reflects the *extent* to which self remains. In addition, some quantitative studies are more suitable for those in the severe stages of dementia, either because they do not rely on verbal abilities (e.g., self-recognition studies), or because they also obtain information from relatives and caregivers (e.g., studies on role-identities). However, many other measures are quite complex, and might be challenging for people in the severe stages of dementia, such as questionnaires or structured interviews which require intact comprehension or verbal skills (e.g., the Tennessee Self-Concept Scale). A further advantage of some quantitative measures is that they potentially enable researchers to explore the relationships between self and other variables, such as cognition, mood, and quality of life, an advantage that has not yet been fully exploited. This would provide valuable information, particularly when considering the clinical implications of research exploring self in dementia.

An issue which is relevant to both qualitative and quantitative studies concerns sample size. Several studies included in the review are based on case studies or rely on small numbers of participants. This presumably reflects the difficulties involved with obtaining large sample sizes in clinical populations, which can be problematic with respect to drawing firm conclusions from the data. While smaller numbers of participants are more typical in some qualitative studies due to the rigorous nature of the analysis, small numbers of participants in quantitative studies can limit the statistical power and therefore the conclusions which can be drawn from these studies, although this issue is often not addressed in study reports. It is therefore important for future studies to aim for a sample size which will satisfy statistical requirements with respect to power, and therefore provide more robust evidence.

Another pertinent question raised by these studies concerns how these different aspects of self actually reflect the construct of self. While some studies examine self as a unitary construct (particularly the qualitative studies), many studies focus on particular components of self or abilities thought to be related to having a sense of self. In some cases it is unclear whether, or how, these components and abilities directly relate to the construct of self. Few of these studies are actually based

on a clear theoretical framework which outlines how the self is conceptualized for the purposes of the research, making it difficult to identify the link between the self and some of the components and abilities targeted by particular studies. Thus, in some cases, it is unclear whether performance on such measures or tasks can be interpreted as a direct reflection of a sense of self. Even where an explicit model or concept of self is utilised in the qualitative studies, such as the social constructionist model, it is not always clear how the evidence interpreted as support for the presence of a self is truly representative of the self. For example, the justification for a direct link between the use of the first person indexical in conversation and an intact sense of self is not obviously clear-cut. It may therefore be more appropriate to refer to the preservation or deterioration of these abilities as such, rather than necessarily interpreting them as a direct reflection of a sense of self. These observations point to the need for further studies to be based on a clear theoretical framework of the self, so that the self can be explored more systematically and so that the measures used more directly reflect a particular construct of self.

Results from studies exploring self in dementia are currently difficult to integrate, which reflects the variety of methods used by researchers in this area. In addition, these studies often involve one group of people at a particular stage of dementia, which limits the generalisation of these results with respect to people at different stages of the disease. Also noteworthy is that while many studies specifically focus on people with AD, other studies use samples of participants with various types of dementia, or who are simply diagnosed as having ‘dementia,’ which is important to acknowledge when considering the generalisability of the findings. However, it is possible to draw some general, if somewhat preliminary, conclusions from existing studies. Almost all of the qualitative studies provide evidence for the presence of self in people with dementia, whether this is presented discursively or through non-verbal behaviours. It appears that at least some people with dementia are able to use personal pronouns, talk about their mental and physical attributes, and demonstrate their multiple personae through speech (Fazio & Mitchell, 2009; Li & Orleans, 2002; Sabat, 2002; Sabat & Collins, 1999; Sabat & Harre, 1992; Small et al., 1998; Tappen et al., 1999). They are also able to construct their identities in social interactions, and are able to use and interpret non-verbal actions in order to interact with meaning and purpose (Hubbard et al., 2002; Saunders, 1998). The authors have argued that these abilities represent a preserved sense of self in people with dementia. However, it

seems that the ability to present a coherent self-narrative is compromised, although not completely diminished, possibly due to the fading of memories as the illness progresses (Mills, 1997; Usita et al., 1998). Many of the participants in these studies are residents in long-term care settings, suggesting that the detection of a sense of self extends to people in the later stages of the disease. The only study which obviously contradicts this conclusion is that of Fontana and Smith (1989), who contend that the self erodes until only 'emptiness' is left. Most of the quantitative studies also present evidence for the persistence of self, although this evidence varies somewhat in nature. It appears that identity is weaker in people with dementia than in healthy older people, with a number of role-identities being forgotten or reduced in significance, although preserved to some extent even in those with severe dementia, (Addis & Tippet, 2004; Cohen-Mansfield et al., 2000; Cohen-Mansfield et al., 2006). There is some agreement that the ability to self-recognise deteriorates as dementia progresses (Biringer & Anderson, 1992; Biringer et al., 1988; Grewal, 1994), and that people with dementia might be inaccurate at rating their own personality traits, particularly people with fronto-temporal dementia (Klein et al., 2003; Rankin et al., 2005; Ruby et al., 2007; Ruby et al., 2008). These results point to a deterioration in various components of self in people with dementia, which is possibly linked to the stage or severity of the illness. Thus overall, evidence from both the qualitative and quantitative studies suggests that the self is preserved at least to some extent in people with dementia, although as a result of the number of models of self employed, this conclusion is based on research which is evaluating a diverse range of behaviours.

It is interesting to note that few studies to date have focused explicitly on the link between the self and the progression of the illness, or the resulting deterioration in cognitive abilities. Most studies on the self in dementia have been based on one group of participants at a particular stage of the disease, although several studies based on self-recognition have highlighted a link between the progression of the disease and a deterioration in this ability (Biringer & Anderson, 1992; Biringer et al., 1988; Fazio & Mitchell, 2009; Grewal, 1994). Fazio and Mitchell also reported that the frequency of pronoun and attribute usage decreased as the level of cognitive impairment increased, but the *rate* of production was actually very similar across groups, since those in the more severe stages of the illness tended to speak fewer words per minute on average. Cohen-Mansfield et al. (2000) also reported that participants' sense of identity deteriorated as the disease progressed and cognitive

abilities declined. Further studies have at least implied that the self, or a particular component of self, would be expected to deteriorate with the progression of the disease. The study by Mills (1997) consisted of eight case studies, and the author concluded that the participants' sense of narrative identity deteriorated as the disease progressed and memory impairments became more significant. Similarly, if identity is modelled as being dependent upon an intact autobiographical memory (e.g., Addis & Tippet, 2004; Naylor & Clare, 2008), one would expect that a person's sense of identity would diminish as the disease progresses and episodic memory deteriorates. Of course, some models of self would not predict a decline in the self even in the face of progressive cognitive deficits, such as 'embodied selfhood' (Kontos, 2004), which emphasizes the way in which selfhood is exhibited through bodily actions, rather than through abilities which require intact cognitive functions. Despite this controversy, the link between severity or stage of dementia and the persistence of self and identity remains relatively unexplored in existing research. While cognitive abilities are clearly affected by the onset and progression of dementia, the influence of this decline in abilities on self and identity remains unclear. This issue is particularly difficult to broach, given that many people with dementia lose the ability to communicate verbally in the later stages of the illness, making it especially challenging to assess the deterioration or persistence of self in these people using the same methods as those which are used with people in the milder stages of the illness. This highlights the need for future research to concentrate on people in both the mild and the more severe stages of the illness in order to elucidate any possible relationship between aspects of the self and the stage of dementia, while using methodologies or measures which are suitable across the range of severity.

On examining results from studies regarding the self in dementia, it is important to take into consideration the type of evidence that is presented, and how it was interpreted by the researchers. It is possible that pre-existing beliefs of the researchers could have influenced the interpretation of evidence or the selection of evidence which is reported. It is apparent that some studies focus on presenting only evidence for the self, or against the self, and do not consider possible contradictory evidence. For example, the Fontana and Smith (1989) study presented results which they interpreted as evidence for the loss of the self. This view was illustrated by reports of a number of observed incidents at the nursing home, including direct quotations from patients, which were gathered over a year-long observation period.

However, in the report, there is no indication of whether these incidents were representative of all of the recorded incidents from the whole year, or whether there was any evidence obtained for the persistence of the self. In addition, on examining the direct quotations from the participants, it is apparent that a researcher approaching the study from a social constructionist perspective might highlight the participants' use of the first person indexical and the multiple personae demonstrated through the reported conversations, and interpret these as evidence for the *persistence* of self. This illustrates the need to be cautious when examining existing evidence, since researchers may have approached the topic from opposing standpoints and with various influences on the way in which information from participants is gathered, reported, and interpreted.

It should be noted that while a vast range of models and concepts of self have been employed in this field of research, there are aspects of self that have been investigated in people with other conditions which have not yet been addressed in people with dementia. For example, aspects of the self studied in people with a diagnosis of schizophrenia which have yet to be thoroughly examined in people with dementia include body image (e.g., Chapman et al., 1978; Weckowicz & Sommer, 1960) and the concept of the ego as being critical for the stability of the self (e.g., Boeker, Kleiser, Lehman, Bogerts, & Northoff, 2006; Rohricht & Priebe, 2004). It is also evident that while studies discussed in this review focus on whether the self is retained or lost in people at various stages of dementia, research into these changes need not be limited to the retention or loss of self. Another interesting possibility highlighted by several studies is that people with dementia continue to possess a sense of self, but that it is based on their pre-morbid sense of self, and has not been updated (Hehman et al., 2005; Klein et al., 2003; Rankin et al., 2005; Ruby et al., 2007). The majority of this evidence is provided by the studies on self-knowledge of personality traits, but warrants further investigation regarding other facets of self-knowledge, or other components of self more generally. Further studies (Clare, 2003; Pearce, Clare, & Pistrang, 2002) have highlighted the possibility that the onset of dementia poses a threat to the self, which is then influenced by how people respond to this threat. These studies suggest that people respond to this challenge in different ways, which can be broadly categorized as self-adjusting, where the self-concept develops to incorporate the changes imposed by the onset of dementia, and self-maintaining, where the emphasis is on holding on to the prior sense of self in order to maximize continuity.

Thus, the self might be influenced by onset of dementia in such a way that it is altered, although not lost. Again, further studies of this type might be valuable in clarifying whether changes to the self necessarily reflect the loss or maintenance of the self per se, or actually represent a shift in the nature of self.

Overall, the vast majority of evidence points to the persistence of self, at least to some degree, throughout the course of dementia. However, there are still many questions which have yet to be answered in this field of research. For example, it is still not known whether the self as a whole is affected by the disease, or whether isolated components of self are affected independently of each other. In addition, it is unclear how the self changes over the disease course, and if the self persists in dementia, whether it is a current or outdated sense of self. These are just a few of the questions which still need to be tackled. In addition to these questions, it is important to explore how a person's sense of self relates to other variables if progress is to be made regarding appropriate interventions and person-centred care for people with dementia.

In conclusion, it can be seen that a variety of methods have been used to investigate the persistence of self in dementia, partly as a direct result of the number of different concepts and models that have been used to understand the self. This is reflected in the range of quantitative and qualitative methodologies employed in these studies, which makes the available evidence in this area rather disparate and somewhat difficult to interpret. Further studies in this area should be based on a clear theoretical framework and consider people at various stages and perhaps with various forms of dementia. It might also be helpful to try to study various components of self separately in order to ascertain whether the self can be considered as a unitary construct, or whether various aspects of the self are affected differently by the onset and progression of dementia. This might help to clarify existing evidence and answer some of the questions outlined above. Such developments could enable researchers to gather more robust evidence regarding the self, which can then be used to inform the development of appropriate interventions and person-centred care for people with dementia.

Chapter 3: Studying the self in dementia: How might we proceed?

Summary

The impact of dementia on the self has become the subject of much research over the last few years, mainly due to the implications for support and care for people with dementia. However, there are a number of limitations of this research that make it difficult to integrate the existing evidence and to draw any firm conclusions regarding the persistence of self. This highlights the need for a different approach to studying the self in people with dementia in order to obtain more robust evidence from future studies. This paper attempts to integrate current research using an existing systematic and comprehensive framework of the self, and outlines the advantages and limitations of using such a framework as the basis for future studies.

Caddell, L.S., & Clare, L. (in press). Studying the self in dementia: How might we proceed? *Dementia*

Introduction

The topic of selfhood in dementia has long been debated, and is certainly not new territory for researchers. However, the problem of defining selfhood has led to difficulties in integrating and interpreting existing research, which in turn makes it difficult to draw any firm conclusions regarding the persistence of self in people with dementia. The aim of this paper is to consider the practicalities of using such a variety of conceptual frameworks in dementia research, and to propose a framework that might enable future research in this area to have a greater impact. In pursuit of this aim, this paper reviews existing research on the self in dementia and the limitations of such research, discusses models of selfhood that have been influential in other fields of research, and then explores the potential benefits of using one of these models to further research in the field of dementia.

Over the last two decades much research has been undertaken to investigate how the self is affected by the onset and progression of dementia. This has become the subject of close attention due to the implications for how people experience and cope with the illness, as well as for how other people treat the person with dementia. In addition, there are implications for the types of treatment or interventions that the person with dementia (and/or the carer) may be offered. Researchers have highlighted the importance of considering the self in person-centred care (e.g. Fazio, 2008; Kelly, 2010; Kitwood, 1997) and already there are several interventions that specifically aim to support self and identity in people with dementia. (Romero & Wenz, 2001; Cohen-Mansfield et al., 2006). In addition to the practical implications, research into the self in people with dementia is of great theoretical interest, in terms of finding out more about the possible construct of self and how aspects of self might be related to each other and to other factors such as well-being or cognitive abilities.

Dementia is a condition that brings to the forefront the philosophical debate about what it means to be a person. Some of the older literature on this topic refers to the notion that selfhood somehow erodes in people with dementia, leading to dehumanisation and the sense that the person no longer remains (e.g. Cohen & Eisdorfer, 1986; Fontana & Smith, 1989). However, much of the more recent literature defends the existence of selfhood in people with dementia, challenging the notion that self and identity disintegrate alongside deteriorating cognitive functioning (see Davis, 2004, and Hughes, Louw & Sabat, 2006, for a detailed discussion of this

debate). In turn, an understanding of how the selfhood of people with dementia is affected is certain to influence the way in which people with dementia are treated by others, including family, friends, and health professionals, and also has practical and ethical implications. Whilst the various standpoints on the self of people with dementia may not be easily reconciled, it is important to conduct research on selfhood in dementia in order to make progress with respect to support and care, and this requires researchers to consider how best to view the self in a way that makes it amenable to evaluation.

Existing research on the self in dementia

Research on the self in dementia has been conducted using both qualitative and quantitative methods. However, the construct of self is difficult to define, and researchers have based their studies on a variety of models and concepts. Qualitative studies have been based upon the social constructionist model (Fazio & Mitchell, 2009; Li & Orleans, 2002; Sabat, 2002; Sabat & Collins, 1999; Sabat & Harré, 1992; Small et al., 1998; Tappen et al., 1999), interactionist perspectives (Fontana & Smith, 1989; Hubbard et al., 2002; Saunders, 1998) and a narrative model of self (Mills, 1997; Surr, 2006; Usita et al., 1998). In addition to this some qualitative studies have been conducted using exploratory thematic analyses, which investigate the self but are not based upon any particular model of self (Beard, 2004; Clare, 2003; Clare, Rowlands, & Quin, 2008; Gillies & Johnston, 2004; Pearce et al., 2002). These studies provide a rich account of the subjective experience of living with dementia, yet there are questions regarding the impact of dementia on the self that are difficult to address using qualitative methods, such as the associations between the self and other variables of interest.

Quantitative studies have attempted to tackle some of these questions, and have tended to investigate specific components of the self, rather than studying self as a unitary construct, as many of the qualitative studies have done. Quantitative studies have examined identity as based on autobiographical memory (Addis & Tippet, 2004; Naylor & Clare, 2008), role identities (Cohen-Mansfield et al., 2000), self-recognition (Biringer & Anderson, 1992; Biringer et al., 1988; Bologna & Camp, 1995, 1997; Fazio & Mitchell, 2009; Grewal, 1994; Mendez et al., 1992; Gross et al., 2004; Hehman et al., 2005) and self-knowledge (Gil et al., 2001; Klein et al., 2003; Rankin

et al., 2005; Ruby et al., 2009; Ruby et al., 2007). In addition to the models and concepts underlying these qualitative and quantitative studies, researchers have posited further theoretical viewpoints with respect to the self in dementia. For example, it has been argued from a philosophical perspective that the person with dementia should be viewed as a 'situated embodied agent' (Hughes, 2001), a viewpoint influenced by the author's experiences as a clinician working with people with dementia. This work also highlights the relevance and practical implications of this topic to the clinician, as well as the ethical challenges faced in deciding how best to view the self in people with dementia.

Limitations of existing research

A recent review (see Chapter 2) found that the vast majority of available evidence in this area points to the persistence of self throughout the course of dementia, at least to some degree, but also highlighted the difficulties created by approaching the subject of self using such a wide range of concepts, models, and methodologies. This disparity in models and methodologies means that the results from these studies are difficult to integrate, making it hard to draw any firm conclusions from the existing body of evidence. In addition to this, it is unclear how some of these aspects of self actually reflect a specific construct of self, since many studies do not outline a clear theoretical framework. For example, studies testing self-recognition in people with dementia may equate this ability to having a sense of self, but there is no underlying framework highlighting the basis for this link. The existing studies also leave a number of questions unanswered. It is currently unclear whether the self is affected as a whole by dementia, or whether different aspects of self are affected independently of each other, since studies have either attempted to measure the self as a unitary construct, or have measured only a single aspect or component of self. There is also little evidence to indicate how a person's sense of self might be related to his/her cognitive abilities, such as aspects of memory functioning and linguistic abilities, or psychological factors, such as mood and well-being. These limitations highlight the need to try to evaluate and integrate current evidence in some way, and to think carefully about how future studies should be conducted in order to obtain a more thorough and structured view of what happens to the self in people with dementia. In doing so, it would seem important to use a clear, systematic, and comprehensive

model of self in future studies. Psychological research has led to the development of a number of systematic models of self that may be useful in this regard. In this review we will, therefore:

- Examine a number of relevant models of the self, in order to suggest a model that might be suitable as a possible framework for research in this area.
- Explore how existing research in this field fits within this theoretical framework.
- Discuss the advantages and limitations of using this type of model for researching the self in people with dementia.
- Consider the implications for future research in this area.

Models of Self

The following sections will review a number of systematic models of self that have been influential in other areas of psychological research, before highlighting one specific model that could potentially be of use in furthering research into the self in people with a diagnosis of dementia.

The early distinction between ‘consciousness’ and ‘self-awareness’

One of the earliest distinctions within the self was described by both Mead (1934) and James (1950), who described two aspects of the self according to the focus of attention - the self experienced through the ongoing stream of consciousness when attention is directed outwards (‘consciousness’), and the self as an object with traits, characteristics, and preferences when attention is directed inwards (‘self-awareness’). Researchers have since continued to define the self with reference to this distinction (e.g. Lewis 1991; Nelson, 2001; Povinelli, 1995), and other researchers have elaborated on this distinction to suggest models of self with more than two components. These include Brown’s (1976) four-level model, Farthing’s (1992) four-level model, and Schooler’s (2002) three-level model of consciousness and the self. Brown’s model consists of two levels of unconsciousness and two levels of

consciousness. The first level of unconsciousness is 'sensorimotor cognition', which reflects a 'deep' level of unconsciousness that a person might experience when in a deep sleep or in a coma. The second is the 'limbic stage', which refers to a 'lighter' sort of unconsciousness, such as when a person is dreaming. The first level of consciousness is the 'neocortical level', which refers to attention directed outwards towards the environment, and the final level is the 'symbolic level', where the person experiences self-awareness. Farthing's model (1992) also reflects the initial distinction between consciousness and self-awareness, with the 'non-conscious mind' representing a low level of consciousness, where the person is not unconscious, but also is not attending to any sensory inputs. 'Peripheral consciousness' represents an intermediate level of consciousness, where mental events are on the borderline of entering full-blown consciousness. 'Primary consciousness' represents consciousness in the sense that a person is able to experience and act on perceptual information, and 'reflective consciousness' infers the ability to reflect on one's own experiences and to be self-aware. Schooler's model (2002) uses the terms 'non-consciousness' to signify a lack of consciousness, 'consciousness' to imply that a person is able to experience sensations and perceptions, and 'meta-consciousness' to describe a person's ability to reflect on their own experiences, signifying self-awareness. It can be seen therefore that there are a number of different models of the self that use the initial distinction between consciousness and self-awareness described by Mead (1934), but which employ different terms to represent equivalent states or levels of the self (for a review, see Morin, 2006).

Models incorporating self-information

Further models have been developed which are based on this same initial distinction, but which also incorporate the type and complexity of self-information to which a person has access, on the premise that very basic self-information can be processed at a lower level of consciousness, whereas more complex self-information can be accessed at a higher level of consciousness (Morin, 2006). Information about the self can take numerous forms, and can include factual information about one's self as well as more subjective representations of one's self. The main distinction here is between perceptual information and conceptual information about the self (Legerstee, 1999). Perceptual information would refer to types of information about oneself that are

available directly through the senses, such as information regarding one's body or one's environment. Conceptual self-information refers to information about the self which is not immediately available through perceptual experiences and is thus represented mentally at an abstract level. Models based on such types of self-information include those of Neisser (1988) and Newen and Vogeley (2003). Both models also stress the importance of time in relation to self-awareness, which would allow a person to link his/her current self with his/her past self and possible future self, a factor which many researchers believe to be an important feature of a person's sense of self (e.g. Fivush, 2001; Harter, 1999; Povinelli, 1995, 2001). Newen and Vogeley's theory (2003) suggests that there are five levels of complexity with respect to representations about the self and the environment. The first level ('phenomenal self-acquaintance') represents the ability to register sensory information in the present and to classify such experiences into properties or states. The second level ('conceptual self-consciousness') involves the classification of objects and properties including the ability to represent oneself and one's mental states. The third level ('sentential self-consciousness') represents the ability to categorise complex events and to experience oneself as participating in them, and the fourth level ('meta-representational self-consciousness') reflects the mental representation of the self and of others whilst also incorporating autobiographical knowledge, moulding these aspects into a coherent framework of the self. The final level ('iterative meta-representational self-consciousness') consists of the ability to construct mental models about other people's models of oneself. Neisser's model (1988) describes five types of 'self-knowledge' that are so distinct that they each establish a different 'self'. The 'ecological self' represents the self with respect to the physical environment, and can be determined directly through perceptions. The 'interpersonal self' represents the self as engaged in social interaction, and can also be perceived on the basis of objectively existing information which signals that the self is involved in an interaction with another. The 'extended self' is the self experienced across time, based on memories of our past self and anticipation of our future self, and is thought to enable a person to experience a sense of continuity. The 'private self' consists of conscious experiences that are not available to anyone else, such as aspects of perception and action, as well as thoughts, feelings and dreams. The 'conceptual self' refers to the self-concept, and is made up of a number of abstract representations about oneself, such as roles, traits,

identity, personal characteristics, and autobiography, and is in effect a drawing together of the other four types of information about the self.

The potential benefits of using Neisser's model of self in dementia research

With respect to using an existing model or framework to guide empirical research regarding the self in dementia, the model of self proposed by Neisser (1988) seems particularly useful for several reasons. This model has been hugely influential with respect to thinking about the self across different fields of research, and is widely cited. However, the work of Neisser (1988) has only been briefly considered in the area of dementia, in relation to the impact of dementia on the self (Jenkins & Price, 1996), the neuroanatomy of the self in dementia (Seeley & Miller, 2005) and person-centred care (Kyle, 2008). This model of self has yet to be used as a theoretical framework on which to base empirical research. Whilst consciousness has also been the subject of investigation in people with dementia, and is intrinsically linked to the self, it can be extremely challenging to measure different aspects or levels of consciousness described in the models above, and in fact most studies of consciousness in dementia have focused on changes in consciousness per se (particularly in dementia with Lewy bodies) without relating these to sense of self (e.g. Ballard et al., 2002; Walker et al., 1999). Neisser's model is primarily based on aspects of self-knowledge, but these aspects can still be related to the main levels of consciousness and self awareness as described by the models outlined above (Morin, 2006). It also offers the advantage of specifying aspects of each component of self that are tangible and can potentially be observed and measured. Neisser's conceptualisation of the self also offers further advantages such as the potential for using this model as a basis for empirical studies and applying the results in a real-world context. This model could therefore provide a much-needed clear, systematic and comprehensive theoretical framework that would be helpful for guiding future research regarding the impact of dementia on the self. This is not to say that Neisser's model is in some way superior to other models of self or identity; merely that it could be useful in terms of progressing empirical research, which would clearly be beneficial with respect to understanding more about the relationships between the self and other variables. Such evidence could then be used to inform or enhance the development of appropriate interventions with the aim of supporting the self, which

are currently in the early stages of development and have a number of limitations. The next section examines Neisser's model in more detail in relation to existing research on the self in people with dementia.

Neisser's model of the self in relation to dementia

As outlined above, Neisser's model of the self consists of five different components of self. The five selves differ in their origins, their developmental histories, in the pathologies that act upon them, and the ways in which they contribute to the social experience of humans. Neisser explains that these selves are not experienced as being separate and distinct from each other, as there is usually stimulus information which creates the feeling of unity. It is suggested that each of these selves develops early in life and exhibits continuity over time, which contributes to the overall feeling of continuity within the self. This section outlines the five components of Neisser's model in more detail and will examine how existing research on the self in people with dementia is related to categories of self proposed by this framework, in order to see how well this research fits with a current, systematic model of self, and to identify the advantages and limitations of this approach. For each of the five components, it is important to consider not only how previous research relates to this component directly, but also to take into account the possibility that the testing procedure itself might require certain components of the self to be intact. This will be discussed in a separate section following the description of the five components of Neisser's model.

The 'ecological self'

This represents awareness of the self as perceived with respect to the physical environment, through the processing of visual, auditory, and kinaesthetic stimuli. The continuous flow of optical information through the visual system means that the entity (the 'ecological self') is constantly aware of its position, posture and movement with respect to the environment. It is also thought that the ecological self is related to the self as an embodied 'agent' - that is, it is able to initiate movements and perceive the consequences in order to observe the effects of acting upon the environment. This specifies that the parts of the body which one is able to move and control are parts of oneself, creating a sense of embodiment.

There are a number of studies which appear to investigate aspects of self that might share features with Neisser's 'ecological self'. The model most commonly used to investigate the self in dementia is the social constructionist model (Fazio & Mitchell, 2009; Li & Orleans, 2002; Sabat, 2002; Sabat & Collins, 1999; Sabat & Harré, 1992; Small et al., 1998; Tappen et al., 1999). This model posits that language is of fundamental importance in the creation of social reality, and also that the way in which we acquire and use language skills can influence the organisation of thought and experience (see Gergen, 1985). The social constructionist model as applied to dementia consists of two (Sabat & Harré, 1992) or three types of self (Sabat & Collins, 1999), depending on which version of the model is used, but only one type of self is relevant here. Sabat and Harré (1992) suggest that there is an individual self consisting of personal identity (Self 1), which may be expressed through the use of personal pronouns, and through which we are able to take responsibility for our actions and experience feelings as our own. It is difficult to judge whether this type of self belongs to the category of 'ecological self', as it is unclear exactly how the use of personal pronouns might be linked to having a sense of self. For example, Sabat and Harré (1992) acknowledge that personal pronouns might be used simply out of habit, rather than as a direct reflection of ownership of one's thoughts and actions. However, the use of personal pronouns could arguably suggest an ownership of one's feelings and bodily actions, and a sense of agency through which one initiates such actions, which does suggest that some features of the 'ecological self' may be indicated here.

One study has used the framework of embodied selfhood to examine the persistence of self in dementia (Kontos, 2004). This theoretical framework (see Kontos, 2003) has been used to challenge the assumption in some cultures that cognition and memory alone are equated with selfhood, implying a loss of selfhood in people with dementia as a direct result of cognitive impairment. Embodied selfhood suggests that the body itself is an important source of selfhood, which does not arise from a cognitive source of knowledge or information. This framework of the self appears to share some features with the 'ecological self' of Neisser's model as it examines the phenomenon of being in a particular place or situation and being in control of one's body, and being able to move parts of the body to interact purposefully with the environment.

The 'interpersonal self'

The 'interpersonal self' is the self as engaged in social interaction with another person, and can be directly perceived through objectively existing kinetic information. This information would come into existence where the nature, direction, and timing of one person's actions coincide with those of the other person/people. According to Neisser (1988), the 'interpersonal self' would be simultaneously accompanied by an intact 'ecological self'.

Several studies have used interactionist models to study the self in people with dementia (Fontana & Smith, 1989; Saunders, 1998; Hubbard et al., 2002), which might be said to share some features with Neisser's 'interpersonal self'. Interactionist models rest on the theory that the self is based on social constructs rooted in interactions (see Mead, 1934). Whilst one study takes a broad interactionist perspective (Fontana & Smith, 1989), other studies specify their approach more precisely. One study approaches the question of identity from an interactional sociolinguistic framework (see Gumperz, 1982), and focuses specifically on capturing conversation in naturalistic settings in order to understand the different ways in which the self is socially constructed in everyday life (Saunders, 1998). Another related approach is the symbolic interactionist perspective (see Blumer, 1969), which has been employed to interpret how non-verbal behaviour is used and defined by people with dementia in social interactions (Hubbard et al., 2002). In addition to Self 1 (see above), the social constructionist model as applied to dementia also outlines the 'selves' (Self 3) that are presented publicly in everyday interactions with others (Sabat, 2002; Sabat & Collins, 1999). A person may exhibit many selves depending upon the particular context, such as a caring relative, a dedicated doctor, or a reliable friend, but these selves rely upon the social cooperation of other people. Neisser's notion of self in social interaction may have some similarities with interactionist and social constructionist models of self in that it acknowledges the importance of social interaction. However, such models go much further than Neisser's model, suggesting that self is constructed essentially within the context of social interactions and relationships.

The 'extended self'

The 'extended self' is the self as it was in the past, according to the memories that we have access to, and as we anticipate that it will be in the future. This might involve episodic memories (each reflecting a unique and specific past event; Tulving, 1972) or general event representations/scripts (where a repeated and familiar routine is remembered; Nelson, 1986; Schank & Abelson, 1977), both of which contribute to the extended self.

A number of studies have examined the autobiographical memories of people with dementia, which might thus be said to represent the 'extended self'. Addis and Tippet (2004) suggest that identity is primarily based on autobiographical memory alone, whereas Naylor and Clare (2008) also examine the relationship between autobiographical memory and the self, but using a social cognitive approach, where the self is viewed as a multidimensional construct, consisting of beliefs, attitudes and information concerning the self (see Greenwald & Pratkanis, 1984; Gergen, 1984; Markus & Wurf, 1987). Both studies use a structured interview to assess autobiographical memory (Autobiographical Memory Interview; Kopelman et al., 1990), which directly tests a person's ability to remember personal experiences (as well as semantic information) across the life span, thus reflecting the notion of the 'extended self' as in Neisser's model.

Similarly, some studies have used a narrative approach as a basis for the study of self in dementia (Mills, 1997; Usita et al., 1998). It has been suggested that self is, or depends on, the ability of a person to construct and communicate a narrative (see Bruner, 1987). The justification for this is that such narratives enable people to define or update their sense of self, thus allowing a sense of coherence and continuity to develop through the integration of life experiences. A socio-biographical approach to self has been used in a single study (Surr, 2006), and represents a combination of social constructionist and biographical, or narrative, perspectives. This theory contends that both relationships and interactions with others, the wider social context, and narrative and storytelling all play a crucial role in the maintenance or undermining of self. These studies rely on the person being able to talk about their memories and life stories/narratives in different ways, which clearly requires the abilities attributed to Neisser's 'extended self'. However, the studies described here go beyond the 'minimum' criteria for the extended self, which just requires the

recognition that one has a past which one can remember, and an anticipated future. These studies also demonstrate how this information can be developed into a narrative, life story, or autobiography, and are therefore also relevant to the 'conceptual self' (see below).

The 'private self'

The 'private self' refers to our conscious experiences (such as thoughts, feelings, intentions) that are not available to other people, and includes both aspects of perception and action and also phenomena which are not related to a person's present circumstances, such as dreams. These experiences can be independent of the 'ecological' and 'interpersonal' selves.

The 'private self' is difficult to assess, because of its inherent inaccessibility to others. The only way that we can examine the 'private self' is through the person in question communicating aspects of his/her 'private self' to researchers. Studies which use a thematic analysis might focus on asking people about certain experiences such as their thoughts and feelings about themselves. A number of studies concerning the self in people with dementia have attempted this type of analysis (Beard, 2004; Clare, 2003; Clare et al., 2008; Gillies & Johnston, 2004; Li & Orleans, 2002; Pearce et al., 2002). Such studies might provide the best insight into a person's inner world, but many of these acknowledge that the methodology involves a degree of interpretation by the researcher in order to make sense of this experience.

The 'conceptual self'

The 'conceptual self' represents a tying together of the other four components of self, and reflects the way in which each person has a particular concept of him/herself. It is made up of abstract representations of oneself, such as roles, traits, identity, personal characteristics and autobiography (Morin, 2006). This aspect of self is based on what one has been told about oneself as a human being in general, and as a person in particular, as well as on what one notices about oneself. There are a number of sub-theories that make up the conceptual self. The first is 'role theories', which reflect our beliefs about how we fit into society. 'Internal models' reflect our beliefs about our

bodies and minds, and 'trait attributions' are theories about the self that may be acquired from our beliefs about our roles and our internal models. These self-theories are distinguishable from the other four kinds of self because they tend to be based on socially established and verbally communicated ideas. Other kinds of experience are also likely to be taken into account, such as our perceptions of our bodies, our interpersonal communication, memories of what we have done in the past, and the meanings of our thoughts and feelings. Thus each of the other four kinds of self are also represented in the 'conceptual self'. As a result of this, a number of studies mentioned below have already been outlined previously, but will be noted again here.

A wide range of studies has tackled aspects of the self that appear to overlap with Neisser's notion of the 'conceptual self'. Several studies have focused on self-knowledge of personality traits in people with dementia (Klein et al., 2003; Rankin et al., 2005; Ruby et al., 2007; Ruby et al., 2008). Klein et al. (2003) suggest that knowledge of one's own personality traits relies on episodic and semantic memory, which implies that the memory difficulties experienced by people with dementia would affect their ability to accurately rate their personality traits. These beliefs about oneself are likely to be based on internal models and roles, as well as what one has been told by others, thus suggesting some sort of self-concept in line with Neisser's 'conceptual self'.

A number of studies have attempted to examine self-recognition in people with dementia, some specifically with the aim of ascertaining whether self persists in dementia (Biringer & Anderson, 1992; Biringer et al, 1988; Bologna & Camp, 1995, 1997; Fazio & Mitchell, 2009; Grewal, 1994; Gross et al., 2004; Hehman et al., 2005; Mendez et al, 1992). These studies usually involve testing participants to see whether they are able to self-recognise using mirrors, photographs, or videotapes. It seems likely that some aspect of the 'private self' would be involved in self-recognition, given that one would have to make the connection between what one is seeing in the mirror and how that relates to oneself, thus requiring certain thought processes and internal events. One might also expect that a person would require some sort of concept of his/her personal appearance in order to relate the person in the mirror to the self. The self-recognition studies have therefore been considered as a possible indication of the 'conceptual self' for the purposes of this article.

The social constructionist model also appears to be relevant to the conceptual self. As mentioned earlier, the multiple social personae (Self 3), are the 'selves' that

are presented publicly in everyday interactions with others (Sabat & Harré, 1992; Sabat & Collins, 1999; Sabat, 2002; Small et al., 1998). These personae might be likened to 'roles' that a person adopts over the lifespan, which could represent the 'role theories' that Neisser mentions as being a part of the 'conceptual self'. The third type of self was introduced to the original social constructionist model being used to investigate the self in people with dementia after the original distinction between 'Self 1' and 'Self 3' was made (Sabat & Collins, 1999). This type of self (Self 2) refers to a person's past and present beliefs and attributes, such as one's traits and abilities. These studies look for evidence of a person's awareness of their physical and mental attributes (Fazio & Mitchell, 2009; Sabat & Collins, 1999; Sabat 2002). Certainly, one's mental attributes cannot be perceived directly which suggests that a representation of these must be built based on other internal models and trait attributions as described in the 'conceptual self' of Neisser's model.

There are a number of other studies that have been outlined in previous sections that also appear to share some features with the 'conceptual self'. These include studies that take an autobiographical (Addis and Tippet, 2004; Naylor and Clare, 2008) or narrative approach (Mills, 1997; Usita et al., 1998) to studying the self in people with dementia, as well as studies that have focused on the types of roles people adopt across the life span (Cohen-Mansfield et al., 2000; Cohen-Mansfield, Marx, Thein & Dakeel-Ali, 2010; Cohen-Mansfield et al., 2006). These roles are likely to be based on the numerous representations that people hold of themselves, and thus clearly reflect the presence of the 'conceptual self'. It is also possible that evidence for the 'conceptual self' (in addition to the 'private self') will be elicited through the studies using thematic analyses, depending upon the focus of the interview questions and how the participant chooses to respond to them.

In one sense, as the conceptual self is made up of components of the other four kinds of self-knowledge, there may be aspects of the conceptual self in all studies which have been mentioned. The five types of self are intrinsically linked, with aspects of one influencing aspects of the other types of self. For example, autobiographical memory and narrative stories might influence the conceptual self, but might also be influenced *by* the conceptual self, as information could be fed back and might influence one's narrative or life story, which are constantly being extended and/or adjusted. Thus it is very difficult to tease apart the effects of the different types

of self-knowledge when doing research with people who come as a 'whole', rather than as people with five different selves which are exhibited separately.

Difficulties related to testing aspects of selfhood in people with dementia

Even with a clear theoretical framework of self on which to base research, there remain some difficulties surrounding testing for the presence of aspects of self empirically. For example, it is clear that some abilities are usually required in order for people with dementia to participate in research. Most research procedures depend upon the person being able to communicate with the researcher and to interact with testing materials as necessary, as well as being aware of his/her embodiment, and having control over the initiation of actions and the ability to perceive the consequences of these actions. It would therefore seem likely that many studies would depend upon the person with dementia having, in terms of Neisser's model, an intact 'ecological' and 'interpersonal' self in order to participate.

It also seems likely that many studies examining the self in dementia rely on the ability of the person to either report his/her internal experiences or act upon them in order to complete a measure or task, whether they are thoughts, feelings, or other kinds of experiences. Studies that ask the participant to respond in some way, by talking to the researcher, answering questions in written format, completing practical tasks, etc, all require some underlying conscious processes. Thus even by interacting with a person through research one is likely to elicit aspects of the 'private self', but directly testing these aspects is an extremely challenging issue. Thus it is likely that most studies with people with dementia will require the participant to have a 'private self' that is intact at least to some degree, whether he/she is specifically being asked to report it or whether it is being used to complete tasks which do not directly involve reflecting on the 'private self'.

These issues would appear to be inherent in most frameworks of the self, rather than being specific to this model, and require consideration when contemplating trying to measure components of self separately. This issue is considered further below.

Discussion

It appears that all existing studies discussed in this article show features of one or more of the categories of the self as described by Neisser (1988). Most, if not all, studies actually display features of more than one category of Neisser's framework, mainly because the majority of this research has been dependent upon some sort of interaction between the participant and the researcher, which automatically fulfils the criteria for the 'ecological' and 'interpersonal' selves. Similarly, most studies rely upon participants' words, actions, and thoughts, which suggest that the 'private self' must be functional in these people. It appears that the majority of studies fall into the category of Neisser's 'conceptual self', as they tend to examine more complex types of self-knowledge that are acquired through interactions, which enable a person to engage with socially established and verbally communicated ideas. These studies have steered away from studying consciousness per se, and concentrated more on complex constructs such as roles and identities. In one sense, this reflects a limitation of using this sort of approach to studying the self, since it is difficult to study each component of self independently without also tapping into the other components of self. This issue will be discussed further below.

Using Neisser's model to try to integrate current research has highlighted a number of difficulties surrounding approaches that have been used to study the self in dementia. Some existing studies do not offer a particular definition of self for the purposes of the research, so it is unclear what is being observed or measured, or what are considered to be components of the self. This is evident where studies attempt to measure or investigate 'the self' as a unitary construct. These studies may actually be using the same term to describe aspects of self that are quite different and dependent upon on a variety of abilities. Issues of this sort make it difficult to integrate existing research as these studies may be measuring quite different abilities and aspects of the self, despite sharing the common term of 'the self'. A related issue is the fact that many studies lack a clear theoretical framework, such that aspects of the self that have been the focus of research may be ambiguous with respect to how they are linked to having a sense of self. For example, there is little agreement on the aspects of self required for recognising oneself in a mirror, such that even where there is consistency in terms of methodology, there is confusion with respect to how the results should be interpreted and how this relates to having a sense of self (Gallup, 1985; Gallup,

Anderson & Shillito, 2002; Mitchell, 1993, 1997, 2002; Morin, 2006). This suggests the need for more clarity in future research with respect to what is being measured and how this relates to the self.

Thus there are a number of advantages and also some limitations to using a theoretical framework such as Neisser's to clarify exactly what is being researched and discussed. This sort of model provides a way of organising research that ties it to a conceptual framework of self. This in turn allows one to link whatever is being tested to a particular construct of self, and avoids the issue with some previous research where the component of self being tested (or the ability which is thought to be related to possessing a sense of self) has no obvious link to a specific model or framework of the self. Another advantage of having a multi-component model of self is that it enables one to test different aspects or specific components of self within the same population, in an effort to establish whether the self is affected as a whole by dementia, or whether components of self are affected independently of each other. If a systematic model was employed, it could also allow researchers to observe relationships between different components of the self, or even within components of the self. The possibility of investigating the self as a number of separate components or processes has also been noted by Klein & Gangi (2010), who suggest that there is no single entity to measure, and that therefore it would be beneficial to break the problem into a number of smaller parts which could be explored separately (see also Klein, *in press*). In this way one could obtain evidence regarding separate components of the self, and then focus on the ways in which these components might interact to produce the experience of a unified self. However, Neisser's model might be limited in this respect since the components are not completely independent of each other, and also because testing procedures typically require abilities relating to certain aspects of self (particularly the 'ecological' and 'interpersonal' selves) in order to be feasible. This makes it challenging to classify most of the existing studies on the self into just a single category of Neisser's model. However, this issue would appear to be inherent in researching the self, and is therefore not specific to this framework. Whichever model is used, it is likely that the participants would have to be exhibiting some degree of consciousness or self-awareness to be able to take part in the study. In addition, most models of the self require a lower or more basic sense of self, consciousness or self-awareness, to be able to experience and exhibit the more complex levels of self, consciousness or self-awareness. This really represents part of

a larger issue in isolating the different components of the self so that they can be tested separately. As the self is generally experienced as a single entity, it is not an easy task to reduce its content to distinct components of self which are independent of each other. However, it might be possible to consider such models of self as being hierarchical to some extent, since the 'higher' levels of self (such as Neisser's 'conceptual self') appear to subsume the 'lower' levels of self (such as Neisser's 'ecological self' and 'interpersonal self'). It might then be possible to investigate the self systematically using this approach, whereby one might conclude that the 'lower' levels of self are likely to be intact if the 'higher' levels of self can be detected and measured. Thus this issue should not necessarily be seen as a barrier to using such comprehensive models of self, given that the benefits of this approach are still numerous. Moreover, undertaking research with people who have impairments in the more complex levels of the self could provide valuable information about how these levels are structured and the nature of the relationships between them.

It is interesting that all of the empirical studies that have been undertaken with people with dementia regarding the self appear to share features with one or more components of Neisser's model. This could be because the framework suggested by Neisser is based on the origin and developmental histories of the different aspects of self, as well as taking into account the pathologies of the self, thus also giving the model a biological basis to some degree. In addition, the way in which each aspect of self contributes to the social experiences of humans has been taken into consideration in the development of the framework. All of these factors taken together have resulted in a model of self that appears true to human experience, and which it is therefore possible to relate to in terms of everyday experiences, as noted by Kyle (2008), who highlighted the potential for each of the components of self to be recognised and understood in terms of everyday observations and interactions. In turn, this has outlined aspects of self in a way that is accessible to researchers, and these aspects of self may be more amenable to measurement than some of the constructs outlined in other models. This is also advantageous in terms of being able understand how dementia might impact upon the self, and to apply results in a practical way to offer understanding, help and support for people with dementia (Jenkins & Price, 1996; Kyle, 2008). If research is able to focus on aspects of the self that are closely related to what people experience on a day to day basis, the results are more likely to offer an

opportunity to develop interventions that are effective and that can be applied in the context of real-world situations.

The self is a very challenging topic to investigate. Although a lot of research is being conducted with the aim of finding out how the self is affected by the onset and progression of dementia, it is difficult to make sense of it due to the disparity in the concepts, models and methodologies being employed. This difficulty is exacerbated by the lack of theoretical framework in some studies, making it difficult to clarify exactly what is being tested and how this relates to the self. This paper has highlighted the value in taking a different approach to address this topic, which makes use of a clear, systematic framework of the self. There are both advantages and limitations of using such an approach. It would allow researchers to address the topic of the self in a more systematic way, which might enable researchers to integrate findings across studies and to relate findings to a theoretical construct of self. It is also important to consider the value of conducting research using a model of self that can be related to everyday experiences, given the implications of this sort of research for the care and support offered to people with dementia. Although this way of studying the self is not free from some difficulties that appear to be inherent in any attempt to measure the self, it would address a number of significant limitations of existing research and enables researchers to think about how best to conduct future research to maximise its impact in terms of theoretical and practical implications.

Chapter 4: Interventions supporting self and identity in people with dementia: A systematic review

Summary

Objectives: Recently researchers have started to focus on ways to support self and identity in people with dementia. The purpose of this review is to discuss the main features of existing interventions aiming to support self and identity in people with dementia, to draw conclusions regarding the effectiveness of these interventions, and to highlight the implications for future research.

Method: Systematic review of intervention studies aiming to support self and identity in people with dementia.

Results: Ten studies met the inclusion criteria. All reported some benefits to participants. There were significant methodological limitations and study quality was generally low. The interventions varied in terms of participant characteristics, content, and outcome measures, making it difficult to draw overall conclusions about effectiveness.

Conclusions: Interventions aiming to support self and identity in people with dementia are currently in the early stages of development. Firm recommendations cannot be made at this time. Further well-designed studies are required to provide more robust evidence.

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Introduction

Recently there has been an increase in research focusing on how self and identity are affected by the onset and progression of Alzheimer's disease and other types of dementia. Research on the self in people with dementia is important for several reasons. It is valuable to try to understand how people with dementia experience themselves and their surroundings, as this has implications for how people cope with the illness, how they relate to others, and how they might respond to different types of intervention. Practical benefits of increased understanding include the implications for optimal care provision (Harnett & Jonson, 2010), for ethical decision-making (Hughes, 2001), and for the conduct of research (Cowdell, 2006). Indeed, research has even suggested that relatives of people with dementia in residential care actually consider the failure to support maintenance of identity in residents as abuse (Harnett & Jonson, 2010). The importance of attributing personhood to individuals with dementia, irrespective of cognitive status or degree of overt responsiveness, is now widely accepted (Fazio, 2008; Kitwood, 1997), but the study of selfhood focuses more directly on the nature of subjective experience. Self and identity have sometimes been operationalised in terms of specific behaviours thought to index self or identity, such as mirror self-recognition (Bologna & Camp, 1997) or self-knowledge of personality traits (Klein et al., 2003), or considered in terms of specific aspects such as self-esteem or self-efficacy. However, in this review we focus on self and identity as broad, general constructs. Some researchers have argued that self and identity diminish or are lost in people with dementia, but the majority have suggested that some aspects of self and identity do remain intact, at least to some extent, over the course of dementia (see Chapter 2 for a review). Supporting self and identity in people with dementia has become a topic of much interest, despite the difficulties inherent in defining and targeting the self, and represents a potential intervention goal. A number of researchers have suggested that it might be important to try to preserve the self of people with dementia in order to improve well-being in some way (e.g. Clark et al., 2003; George, 1998; Harrison, 1993; Ronch, 1996). As a result, work has been undertaken to investigate ways in which self and identity can be supported in people with dementia, but this work is extremely heterogeneous in terms of methodology. The purpose of this paper is to review interventions which aim to support self and identity in people with dementia in order to examine the ways in which this target has

been pursued, and the quality of the resulting research, and to consider the implications for the improvement of current strategies or development of further strategies to assist with the care and support of people with dementia.

The specific objectives of this systematic review are:

- To identify existing interventions aiming to support self and identity in people with dementia.
- To discuss the main features of these interventions, including the aims and nature of the intervention, outcome measures, results and conclusions drawn from each study.
- To draw conclusions regarding the effectiveness of such interventions to date.
- To highlight possible limitations of existing interventions and identify possible directions for future research.

Method

The databases PsycINFO, MEDLINE, ASSIA and CINAHL were searched on 12th April 2010, and again on 5th January 2011, using the terms ‘Alzheimer’s’ or ‘dementia’ in the title, plus ‘self’, ‘identity’ or ‘personhood’ in the full text. Reference sections of the identified papers were scrutinised for additional relevant studies.

The criteria for inclusion in the review were:

- The paper has been published in a peer-reviewed journal.
- The paper describes an intervention where all study participants (with the exception of control group participants) have a diagnosis of dementia (including fronto-temporal dementia, Alzheimer’s disease, vascular dementia, mixed Alzheimer’s disease and vascular dementia, or ‘senile dementia’).
- The aim of the intervention (or one of its aims) is specifically stated as supporting self or identity in people with dementia, or where this is not the case, the paper discusses self and identity in relation to the intervention.
- The article is written in English.

Results

In total, 39,543 papers were identified using the search terms outlined above. Titles and abstracts were screened and 39,501 were rejected as clearly failing to meet inclusion criteria. Full text was obtained and scrutinised for 42 studies, after which 32 were rejected because they were not intervention studies. Ten studies met the inclusion criteria. These are summarised in Table 1. The studies fell into three groups: studies which aim to support self or identity, but used no outcome measures (Group 1 studies); studies where this was not described as a specific aim of the study, but where the intervention was theoretically linked to self or identity (Group 2 studies); and studies that specifically stated that the aim was to support self and identity, and used outcome measures (Group 3 studies). These three groups of studies will be described separately below, and will be followed by a section examining the main features of the group of studies as a whole.

Table 1. Studies aiming to support self and identity in people with dementia

Authors	Aim of study	Participants	Design	Intervention	Outcome measures	Results
Studies aiming to support self and identity but do not use outcome measures						
Johnson et al. (1992)	Providing possibilities for patients to experience independence and community, focusing on strengths, increasing self-esteem, offering opportunities for expression.	No specific number stated as patients were free to choose each day whether they wished to participate in the group or not, thus the group varied each day.	Post-intervention evaluation of the advantages and challenges of group therapy in the creative arts.	Regular creative art therapy sessions were held at a special care unit for people with Alzheimer's disease. Patients were able to use materials including paints, and to engage in collaborative projects with other patients (e.g. group collages).	No formal outcome measures were used. The therapists made judgements on how well the group was progressing with the aims of the group.	The authors suggested that creative arts therapies can add meaning and value to the patients' experiences, whilst forming a scenario which is free from expectations and social constraints.
Harlan (1993)	Primary aims of art therapy are to help preserve a sense of identity, allow emotional expression, and to interact with peers.	No specific number of patients attending the group was stated as it varied from session to session, but at the group described in the paper there were 6 patients present.	Post-intervention evaluation of the benefits of art therapy for people with dementia according to therapist.	Regular sessions were held for people with different disabilities, including Alzheimer's disease. Materials used included paints, pastels, pencils and sculpture materials.	No formal outcome measures were used. The therapists made judgements on how well the group was progressing with the aims of the therapy.	The therapist suggested that artwork of people with dementia expressed remaining strengths of the participants, and offered an opportunity for communication. It may also allow them to cope with an environment that has become frightening, and allow them to temporarily consolidate the self and gain a sense of control. The therapy was also said to be effective in enhancing motivation, confidence, overcoming isolation, and gaining an opportunity to 'hold on to part of themselves for a little while longer'.
Jensen & Wheaton (1997)	To combine the modalities of music, movement, and visual art-making into a multisensory intervention 'in the hopes of eliciting a response of emotional or affective recall and reminiscence, thereby strengthening a sense of identity and recognition for the person who has Alzheimer's disease'.	People at varying stages of Alzheimer's disease (early-middle stage) and related dementias who attended an art therapy class, most of whom were permanent residents at the nursing home.	Evaluation of group therapy intervention. No outcome measures.	Weekly 90-minute sessions were held for at least 6 months. A variety of music and movements were used at the beginning of each class, and were followed by a drawing task that was mostly focused towards reminiscence. At the end of the class time was allowed for sharing the artwork and related memories.	No formal outcome measures were used - the art therapist judged the progress made during the class based on the individual. Two participants in particular were discussed in detail in the report.	The therapist noted that although there was variety in response to the intervention, for most participants remote memory was stimulated and activity level was increased. It was suggested that the class served as a reminder of their healthier, more productive selves and increased self-esteem.

Studies which mention self or identity in relation to the study but not as a specific aim, and which use outcome measures						
Sherratt et al. (2004)	To 'examine the impact of social interaction in music listening'. Authors examined the potential for music to maintain personhood.	24 people with dementia in the moderate to the severe stages of the disease. 16 were resident on a continuing care ward and 7 attended a day hospital. One participant attended both.	A repeated measures design with four conditions.	Each participant was exposed to each condition. The conditions were: no music; a taped selection of commercially recorded music; a taped selection of the same music recorded by a musician; a live performance of the same set of music performed live by the same musician. Each selection lasted one hour.	Dependent variables were the emotional and behavioural response of participants in terms of engagement, type of response to the music, levels of individually defined challenging behaviours, and levels of well-being and ill-being. These variables were measured through direct observation.	Participants spent significantly longer responding to the music during the live music condition than any other music condition. Levels of well-being were observed for longer in the live music condition. No differences were found across conditions with respect to the duration of challenging behaviours. Higher MMSE scores were related to levels of social interaction and higher well-being.
Irish et al. (2006)	To explore the effect of music on stimulating autobiographical memory (ABM) in people with Alzheimer's disease. ABM is noted as being integral to self-concept and a cohesive identity.	10 people in the mild stages of Alzheimer's disease and 10 healthy older adults.	All participants took part in each of two conditions- a music condition and a silence condition.	Participants were asked to complete all outcome measures under each condition. In the music condition a 10-minute section of Vivaldi's 'Four Seasons' music was played on loop in the background. The order of conditions was counterbalanced.	State Trait Anxiety Inventory (STAI) Autobiographical Memory Interview (AMI) Galvanic skin response technique (GST) Sustained Attention to Response Task (SART)	STAI showed lower anxiety in people with dementia in the music condition but not controls. People with dementia showed significant improvement on the overall AMI score, whereas healthy older people did not. There were no significant changes in GSR in either group, i.e. no change in arousal. In the SART people with dementia made more omission errors in the silent condition than healthy older people, but there was no difference between groups on commission errors.
Yasuda et al. (2009)	To allow caregivers to perform reminiscence therapy at patients' homes or institutions, which should allow increased feelings of self esteem and well-being	15 people with Alzheimer's disease who were outpatients.	An ABCA design was used, where A was the photo video condition, B was a TV variety show, and C was a TV news show.	Each of the conditions lasted for 10 minutes; thus the whole study lasted 40 minutes. Participants watched the four shows in a room by themselves.	The participants' faces and upper body were recorded on digital videotape, which were later evaluated. Responses were measured as 'concentration' and 'distraction' scores. Subcategories were 'gestures', 'facial expressions', 'utterances', and 'eye opening/direction of gaze'.	12 participants completed the intervention. Nine participants obtained the best scores for concentration for their photo video (First showing) and 5 subjects' second highest score was for the second showing of their photo video. The distraction scores were highest for the TV news show, then the TV variety show.

Studies that specifically state the aim as supporting self and identity in people with dementia and which also use outcome measures

Romero & Wenz (2001)	To 'maintain the sense of personal identity, continuity and coherence in patients with a progressive dementia for as long as possible.' To reduce loss of confidence in social interaction, withdrawal, depression, apathy, agitation, aggression and to facilitate participation in daily life	43 patients and 43 caregivers. Patients had a diagnosis of AD or mixed dementia. Mean age 70 years. Mean MMSE of 14 (Range 0-29).	Cohort- uncontrolled	A short-term residential treatment (4 weeks). 4 main components: Psychotherapeutic support, self-knowledge training, facilitation of satisfying everyday activities, and validating communication in care-giving.	Measures completed immediately before and after intervention Cornell Depression Scale CERAD Behaviour Rating Scale for Dementia (BRSD) Nurses Observation Scale for Geriatric Patients (NOSGER): - Mood - Instrumental activities of daily living - Social behaviour - Disturbing behaviour - Self care - Memory	Depression, disturbances in social behaviour and psychopathological symptoms were reduced at follow-up. There were no significant changes in memory functioning, activities of daily living, and self-care.
Cohen-Mansfield, Parpura-Gill, & Golander (2006)	The aim of the intervention was to enhance self-identity and well-being, including mood and involvement in activities, and to decrease agitation.	93 people with dementia from day centres or in nursing homes, assigned to treatment group (52 participants) or control group (41 participants). Mean age 87 years, mean MMSE 10.6.	RCT	Participants, staff and family caregivers were interviewed to establish the most prominent identity role. This information was used to design individual personalised interventions for each person in the treatment group. Treatment was delivered for 30 mins per day for 5 days. The control group received the usual activities and care.	Collected over 5 days prior to, and following, intervention Self identity awareness single question: - Research assistant (RA) rating - Care staff rating Lawton's Modified Behavior Stream- observation scale (LMBS): - Anxiety scale - Sadness scale - Anger scale - Pleasure scale - Interest Scale Multidimensional Observation Scale for Elderly Subjects (MOSES): - Depression/Anxiety scale (RA rating)	The intervention group manifested greater pleasure and interest during treatment than at baseline and than in the control group. Greater involvement was also recorded in the treatment group compared to the control group, and a decrease in disorientation and agitation and a greater awareness of identity were seen in the treatment group but not the control group. No significant changes were seen in anxiety, sadness, anger, depression, withdrawal, compared to the control group.

					<ul style="list-style-type: none"> - Depression/Anxiety scale (Staff rating) - Irritability scale (RA rating) - Irritability scale (Staff rating) - Disorientation scale (RA rating) - Disorientation scale (Staff rating) - Withdrawal (RA rating) - Withdrawal (Staff rating) <p>Agitation Behavior Mapping Instrument- observation scale (ABMI):</p> <ul style="list-style-type: none"> - Involvement item - Agitation scale 	
Haight, Gibson, & Michel (2006)	The life review/life storybook intervention 'seeks to preserve personhood by reinforcing personal identity through conversation and preservation of tangible reminders of a person's lifetime experience'.	30 people with dementia in care homes allocated to treatment group (15 participants) or control group (15 participants). Mean MMSE 17.84.	RCT	<p>This intervention involved a combined approach where participants took part in life review sessions and created a life storybook with the help of care staff. One hour per week was spent on life review for 8 weeks.</p> <p>The life storybook was created with care staff using photographs and explanatory captions. The control group received usual care.</p>	<p>Collected at week 1 and week 8</p> <p>Mini Mental Status Exam (MMSE)</p> <p>Cornell Depression Scale</p> <p>Alzheimer's mood scale (AMS): Negative mood, positive mood</p> <p>Communication Observation Scale (COS)</p> <p>Functional Independence Measure (FIM)</p> <p>Memory and Behaviour Problems Checklist (MBPC)</p>	<p>Significant differences between experimental and control groups were seen on cognition (MMSE), depression, positive mood, and communication.</p> <p>No significant differences were seen for independence or in memory or behavioural problems.</p>
Massimi et al (2008)	To examine how technology may help 'remediate identity through the provision of an external aid to memory and conversation'.	Single patient, 84 years old. Moderate stage of Alzheimer's.	Pre/post test single case design	<p>This intervention used an in-home display called a 'biography theatre' to display the participant's life history in his own home.</p> <p>The participant first took part in approximately 8 sessions with the</p>	<p>Collected at baseline, after collection of biographical material, and 4 weeks after installation of Biography Theatre:</p>	Interim assessment showed an increase in self-identity and a decrease in apathy. Depression, anxiety, general cognition and autobiographical memory remained stable.

researcher, where photos were selected and arranged into themes which would form the basis of the biography theatre. The biography theatre was then displayed on a touch –screen computer in the participant’s own kitchen, which was permanently on and could be viewed whenever the participant desired.

Autobiographical Memory Interview

Informant questionnaire of Cognitive Decline in the Elderly

Self-Image Profile-Adult

Twenty Statements Test

Geriatric Depression Scale

Apathy Evaluation Scale

Goldberg Anxiety Scale

Modified Caregiver Strain Index

Final assessment showed continued improvement on identity, with a slight rise in apathy but stable levels of depression, anxiety and cognition.

Description of studies

Group 1 studies

Three studies fell into this group, where the study aimed to support self and identity, but did not use outcome measures of any type. These tended to be arts-based therapies which relied on the therapist's assessment of the progress and effect of the intervention (Jensen & Wheaton, 1997; Johnson, Lahey, & Shore, 1992; Harlan, 1993).

Art therapy was offered to people with Alzheimer's disease in Special Care Units in the study by Johnson et al. (1992), where the priorities were to support independence and a homely atmosphere, to focus on residents' remaining strengths and abilities, to increase self-esteem, and to offer opportunities for socialisation, expression, and spontaneity.

Harlan (1993) also described an art-based intervention for people with dementia which took place regularly, although the setting is unclear. The author described the primary goals as helping participants to preserve a sense of identity, and supporting self-expression. Participants used paints, pastels, pencils and clay in the sessions. The therapist suggested that the art group enabled people with dementia to draw on their remaining strengths, and used the session as a positive way to cope with what might be a frightening environment for some participants.

Jensen & Wheaton (1997) used an intervention that combined a number of modalities (music, movement, and visual art). The intervention took place during weekly 90 minute sessions in a nursing home, and lasted for approximately six months. Classes included a variety of movements and music at the beginning, which were followed by a drawing task that tended to be based on reminiscence. There was time for discussion of the artwork and sharing of memories at the end of most classes.

Group 2 studies

Three interventions fell into this group, where supporting self and identity was not described as a specific aim of the study, but the authors explained why the intervention might be expected to support self and identity.

One study examined the effectiveness of personalised reminiscence photo videos for individuals with dementia, compared to two other types of television shows (Yasuda, Kuwabara, Kuwahara, Abe, & Tetsutani, 2009). The aim of the study was to obtain the same benefits associated with reminiscence therapy, but using an intervention that did not rely on caregiver supervision. The videos were based on old photographs of the participant, with music played in the background and narration added. The photographs were arranged chronologically and each video lasted for about ten minutes. The researchers compared the responses of the participants watching their photo videos to their responses watching two other types of television programme- a TV variety show and a TV news show, which also lasted 10 minutes.

Irish et al. (2006) explored the potential of music to stimulate autobiographical memory in people with Alzheimer's disease, and suggested that autobiographical memory (ABM) is 'integral to self-concept and a cohesive identity'. The music used for the study was the first movement 'Spring' from Vivaldi's 'Four Seasons', which has a duration of approximately 10 minutes. This was played on loop during the session (in the music condition) as a background stimulus whilst the participants completed the measures. The order of music and silence was counterbalanced and participants were seen twice, a week apart.

Sherratt, Thornton, & Hatton (2004) also explored responses to music in people with dementia. They suggested that listening to music has the potential to maintain personhood, even in those who are cognitively impaired. However, they were concerned that listening to recorded music did not replicate the social and interactive qualities of listening to live music, thus threatening the maintenance of personhood. In this study, the effects of live music and taped music were compared. During the different music conditions, the researchers recorded participant behaviour across six different dimensions, including levels of well-being, level and type of any activity, response to music, physical location, interaction with others, and individually defined challenging behaviours.

Group 3 Studies

Four very diverse studies fell into this group, which specifically stated that the aim was to support self and identity, and used outcome measures.

Romero & Wenz (2001) developed an intervention based on the concept of 'self-maintenance therapy', which consisted of a four-week residential programme to help people with dementia and their caregivers prepare for the future. The aim of the intervention was to maintain personal identity, continuity, and coherence in people with dementia, and to reduce loss of confidence, withdrawal, depression, apathy, agitation and aggression. There were four main components to the treatment, which consisted of psychotherapy, training in self-knowledge, the facilitation of everyday activities, and communication in caregiving.

Cohen-Mansfield et al., (2006) used an individualised approach whereby treatment based on role-identities was tailored to each participant according to his/her most prominent identity role. The aim of the intervention was to enhance self-identity and well-being, including mood and involvement in activities, and to decrease agitation. Treatment was delivered to participants in the treatment group for 30 minutes per day for 5 days, during which the participants were engaged in interactions relating to their role identities.

One intervention involved a combined approach where participants took part in life review sessions and created a life storybook with the help of care staff (Haight, Gibson & Michel, 2006). The aim of the intervention was to preserve personhood through the reinforcement of personal identity in people with dementia. The life review intervention was conducted for one hour per week for eight weeks, and following this the life storybook was created with care staff using personal photographs and captions.

Massimi et al., (2008) developed an intervention which used an in-home display called a 'biography theatre' to display the participant's life history in his own home. The aim of the study was to explore whether technology could support the remediation of identity through the use of an external memory aid. The study was a case study, with a single male participant in the moderate stages of Alzheimer's disease. The participant first took part in approximately 8 sessions with the researcher, where photos were selected and arranged into themes which would then form the basis of the biography theatre. The biography theatre was then displayed on a touch-screen computer in the participant's own kitchen, which allowed the participant to select a particular life period to review.

Characteristics of all studies

Rationale for interventions

All studies explain the rationale behind the interventions to some extent, with similarities and differences in the reasoning on which interventions are based. The primary aims of the studies tended to be to support self and identity, with secondary aims mainly involving improving aspects of well-being. Several interventions were based on the premise that stimulating memory would somehow serve to support a person's identity. The rationale for using a multi-sensory art intervention (Jensen and Wheaton, 1997) was that enabling individuals with Alzheimer's disease to focus on their remaining strengths (such as intact senses) can be used to stimulate remote memory, thus potentially providing a means of accessing sense of identity. Haight et al. (2006), Yasuda et al., (2009), and Massimi et al. (2008) developed interventions that used reminders of a person's life to stimulate memory, and Johnson et al. (2006) also tried to preserve autobiographical memory using music as a stimulus, with the belief that this could lead to an improved sense of identity. Haight et al. (2006) used a life review and life storybook intervention on the basis that personal identity could be reinforced through conversation and the gathering and preservation of tangible items such as photographs that could remind a person of different aspects of their life. Massimi et al. (2008) used a computerised reminiscence approach, with the rationale that the participant's autobiographical memory would improve as a result of reminders about important aspects of his life, enabling him to talk about his past more effectively and hence improving his sense of identity. Similarly, Yasuda et al. (2009) used personal photographs of participants in a photo video in an effort to stimulate interest from the participants. Romero and Wenz (2001) also used memory as a key feature of their intervention by attempting to help their participants retain important information about themselves, on the basis that knowledge of this information would support a sense of identity.

Some of the interventions used an approach that took into account the importance of group interactions (Jensen & Wheaton, 1997, Johnson et al., 1992; Harlan, 1993) and relationships with family members (Romero & Wenz, 2001), with the aim of maximising potential gains by enabling new social ties to form, or by supporting more established relationships during the period of change associated with

the progression of dementia. Another important theme involved maximising remaining skills in planning activities (Cohen-Mansfield et al., 2006; Jensen & Wheaton, 1997; Harlan, 1993; Romero & Wenz, 2001), such that participants could utilise their remaining skills to the best of their ability, thus instilling a sense of achievement and competence.

Researchers also described various other rationales for the content of their interventions. Romero and Wenz (2001) described the importance of stabilising the self in people with dementia. This is achieved by utilising cognitive abilities to maximum effectiveness, avoiding negative emotions resulting from the discrepancy between expectations and experience, and increasing the occurrence of events that are congruent with the self-concept. Cohen-Mansfield et al. (2006) aimed to support participants' sense of identity by designing individual interventions according to the salience of the person's present role identities. Basing the intervention on information about the person's identity was expected to strengthen sense of identity.

Concepts/models of self employed

Only four of the studies referred to a specific concept of self. Romero and Wenz conceptualised the self as a cognitive schema which stores and updates information about the person and about his/her environment, and incorporates a person's abilities, cognitive functions and attitudes (Romero & Wenz, 2001). Cohen-Mansfield et al. (2006) defined identity as the roles that people take on throughout their lives, which can be demonstrated through speech and behaviour. Massimi et al. (2008) defined identity as an internal self-concept which arises from both autobiographical memory and personal semantic memory, in conjunction with how one sees oneself in relation to other people. Similarly, Johnson et al. (1992) subscribed to the idea that memory plays an important part in the maintenance of identity. Sherratt et al. (2004) did not describe a specific model of self or identity for their study, but did outline a theoretical framework that was based on Kitwood's (1997) theory of personhood.

Thus there are some similarities and some differences in the concepts of identity that have been used in these studies. Identity is viewed as something which may be socially established or socially expressed (Cohen-Mansfield et al., 2006; Massimi et al., 2008) and sometimes as being dependent upon memory (Johnson et al., 1992), particularly autobiographical memory (Massimi et al., 2008; Romero &

Wenz, 2001). However, only Romero and Wenz speak about abilities and attitudes, and only Cohen-Mansfield et al. (2006) specifically focus on roles. It is clear that definitions of identity vary, while in some cases no definitions are outlined. It follows from this that whilst all researchers refer to identity, they may not all be referring to exactly the same thing. It is important to consider this when trying to integrate the results of the studies, which is made more challenging by the fact that different definitions of identity have been used.

Design

Design of the interventions was generally weak. The art-based interventions had no comparison group and presented no outcome data, so it was very difficult to quantify the possible effects of these studies. Other studies used different conditions or a control group to further elucidate the effects of the intervention (Sherratt et al., 2004; Irish et al., 2006; Yasuda et al., 2009). The two RCTs (Cohen-Mansfield et al., 2006; Haight et al., 2006) were evaluated for risk of bias using the criteria outlined in the Cochrane Reviewers' Handbook. In both cases it is unclear how participants were randomly assigned to groups, whether or how the allocation to groups was concealed, and whether researchers were blind to condition when assessing the participant at the end of the intervention. These factors could potentially introduce bias to the study. It is certainly noteworthy that in the vast majority of measures where both staff and research assistants recorded scores in Cohen-Mansfield et al. (2006), the research assistants recorded greater improvement than the care staff, with large discrepancies seen in some outcome measures (specifically the self-identity awareness question, and measures of mood, irritability and withdrawal). One of the RCTs accounted for any incomplete outcome data due to exclusions or attrition (Cohen-Mansfield et al., 2006), whereas the other did not (Haight et al., 2006), but both RCTs reported the results from all measures and did not appear to have any other obvious possible source of bias. Limitations of the case study (Massimi et al., 2008) design include the lack of control for other events that might influence the outcome.

It appears that all studies included in the review exhibit some problematic design issues which limit to some extent the conclusions that can be drawn from these studies. This highlights the need for further studies to be based on a rigorous design and as far as possible to be free from the possibility of bias.

Participants

The studies showed considerable heterogeneity in participant characteristics. The number of participants ranged from a single case (Massimi et al., 2008) to 93 participants (Cohen-Mansfield et al., 2006) with the other studies falling somewhere in between, although two studies reported the activities of ongoing therapy groups and thus did not disclose precise numbers of participants (Harlan, 1993; Johnson et al., 1992). Five studies characterised their samples in terms of the Mini Mental State Examination (MMSE; Folstein et al., 1975) a brief cognitive measure with a maximum score of 30 that is commonly used to assess patients with dementia to measure the severity of impairment. Scores ranged from an average of 10.6 (indicating moderate to severe dementia; Cohen-Mansfield et al., 2006) to 21.6 (indicating mild dementia; Irish et al., 2006). Only Yasuda et al. (2006) and Romero & Wenz (2001) provide the range of MMSE scores (mean 14.3, range 0-23; mean 14, range 0 – 29 respectively); with such a broad range of severity included, it is possible that response to intervention may have differed according to severity. In the absence of explicit information about dementia severity (Jensen & Wheaton, 1997; Johnson et al., 1992; Harlan, 1993; Massimi et al., 2008), there is no way of determining which approaches are more or less suitable for individuals at different stages of severity.

Intervention characteristics

As Table 1 shows, the format of the interventions was variable. Three were group-based (Jensen & Wheaton, 1997; Johnson et al., 1992; Harlan, 1993), six were conducted with individuals (Cohen-Mansfield et al., 2006; Haight et al., 2006; Irish et al., 2006; Massimi et al., 2008; Sherratt et al., 2004; Yasuda et al.) and one used a combination of group and individual treatment (Romero & Wenz, 2001). In two studies (Cohen-Mansfield et al., 2006; Romero & Wenz, 2001) the intervention (or at least part of it) was tailored to the individuals, whereas in other studies all participants received the same intervention. Most interventions had more than one component or phase (Haight et al., 2006; Jensen & Wheaton, 1997; Romero & Wenz, 2001; Massimi et al., 2008), or several conditions (Sherratt et al., 2004; Irish et al., 2006; Yasuda et al., 2009), whereas one did not (Cohen-Mansfield et al., 2006). Another major difference between interventions is the setting. One study involved a four-week

residential stay (Romero & Wenz, 2001), whereas others were conducted in residential homes or assisted living facilities (Cohen-Mansfield et al., 2006; Haight et al., 2006; Jensen & Wheaton, 1997; Sherrat et al., 2004), special care units (Johnson et al., 1992), day centres (Cohen-Mansfield et al., 2006, Sherrat et al., 2004), at a hospital (Yasuda et al., 2009) or in the participant's own home (Massimi et al., 2008). There were also differences in the length of the intervention. The interventions ranged from around 40 minutes on a single day (Yasuda et al., 2009), to 6 months of weekly sessions (Jensen & Wheaton, 1997), although it should be noted that the intensity of the sessions also varied across interventions from daily (Cohen-Mansfield et al., 2006; Romero & Wenz, 2001) to weekly (Jensen & Wheaton, 1997; Haight et al., 2006), so the number of sessions might be a better indicator than the length of the intervention with respect to the degree of participation involved in each intervention. The most intense intervention in terms of participation appears to be the intervention involving the residential stay (a full day of activities each day for four weeks; Romero & Wenz, 2001), with the least time spent participating in the intervention being in the reminiscence photo video study where the study lasted for 40 minutes (Yasuda et al., 2009). It is difficult to be certain of the exact amount of time spent by participants in some studies either because there is not enough detail in the paper to be certain (Jensen & Wheaton, 1997; Johnson et al., 1992; Harlan, 1993), or because the intervention was also available to participants during unsupervised time, such as the biography theatre, to which the participant had access at all times (Massimi et al., 2008).

Outcome measures

Three studies lacked formal outcome measures, as progress was determined by the impression of the therapist (Jensen & Wheaton, 1997, Johnson et al., 1992; Harlan, 1993). Other studies which had not specified targeting self and identity as a primary aim tended to rely on observational methods (Sherratt et al., 2004; Yasuda et al., 2009) or in the case of Irish et al. (2006) various measures including anxiety, autobiographical memory, arousal, and attention. Where standardised measures were used, one would expect that for interventions that were specifically aiming to support identity, at least one measure of identity would be used. However, this was not always the case. Cohen-Mansfield et al. (2006) used the Self-Identity in Dementia

Questionnaire (Cohen-Mansfield et al., 2000) as well as a separate question referring to awareness of identity. Massimi et al. (2008) used the Self Image Profile - Adult (Butler & Gasson, 2004) and Twenty Statements Test (Kuhn & McPartland, 1954), although their participant was unable to complete the latter. The other studies did not include a measure of identity, although all studies in this group included measures of depression and several also included measures of anxiety (Cohen-Mansfield et al., 2006; Massimi et al., 2008), apathy (Massimi et al., 2008; Romero & Wenz, 2001), agitation (Cohen-Mansfield et al., 2006; Romero & Wenz, 2001), behavioural disturbances (Cohen-Mansfield et al., 2006; Romero & Wenz, 2001; Haight et al., 2006) and activities of daily living (Romero & Wenz, 2001) or functional independence (Haight et al., 2006). Other outcomes measured were memory functioning (Massimi et al. 2008; Romero & Wenz, 2001), irritability, disorientation, withdrawal, pleasure and involvement (Cohen-Mansfield et al., 2006), and communication (Haight et al., 2006).

Thus the selected measures appear to fall into several broad categories: identity, well-being, behaviour, and cognitive functioning. Some studies tended to focus on various aspects of well-being, and it is apparent that sense of identity is automatically being equated with well-being in some studies; in Massimi et al. (2008), the measures of identity used (Twenty Statements Test, Self Image Profile- Adult) are actually classified for the purposes of the study as being measures of well-being. For studies with no measure of identity, this would appear to be a major limitation in terms of evaluating the outcome of the intervention. One might be able to conclude that the intervention was responsible for changes in well-being, but without a measure pertaining to identity it would not be possible to see whether there was a concurrent change in sense of identity, or indeed whether a change in sense of identity mediated any changes in well-being. In this situation it is not possible to evaluate the intervention in terms of its stated aims.

Study findings

All studies describe some benefit of the intervention for the participants with dementia, but the precise details vary across studies. Each of the three art therapy interventions reported positive results based on the judgement of the art therapist, suggesting improvements in activity level and self-esteem (Jensen & Wheaton, 1997)

an opportunity for communication and enhanced motivation, confidence, and identity (Harlan, 1993), and the opportunity to add meaning and value to daily experiences (Johnson et al., 1992). However, with no formal outcome measures it is not possible to confirm or quantify these effects. Studies which did not explicitly state that they were supporting self and identity reported improved social interaction and wellbeing (Sherrat et al., 2004), lower anxiety, improved autobiographical memory and sustained attention (Irish et al., 2006), and improved concentration (Yasuda et al., 2009). Of the studies which measured identity in some way, Cohen-Mansfield et al. (2006) found that participants had become more aware of their identity (large effect size), although this improvement was only noted by research assistants, and care staff reported no difference in residents' awareness of their identity when making parallel ratings. Massimi et al. (2006) observed a more positive self-image in their participant, which was equated with an improvement in sense of identity. In terms of well-being, two studies noted an improvement in symptoms of depression, with medium to large effect sizes (Haight et al., 2006; Romero & Wenz, 2001), whereas others reported no statistically significant change in either depression or anxiety (Cohen-Mansfield et al., 2006; Massimi et al., 2008). However, the levels of anxiety and depression in these latter studies were low at baseline, leaving little opportunity for improvement during or after the intervention. A reduction in agitation (small to medium effect size), disorientation (medium to large effect size), withdrawal (small effect size; Cohen-Mansfield et al., 2006) and apathy (Massimi et al., 2008) were recorded. No significant changes in activities of daily living were recorded (Romero & Wenz, 2001), but Cohen-Mansfield et al. (2006) did find greater involvement in activities in the intervention group, as well as greater interest and pleasure in activities relative to the control group (large effect sizes). In terms of memory functioning, two studies found no significant change (Romero & Wenz, 2001; Massimi et al., 2008), although one study found an increase in MMSE score, with a large effect size (Haight et al., 2006).

Overall, no outcomes produced consistent changes across studies, although all studies have described some benefit for the participants. However, there are a number of issues that are important with respect to this conclusion. Firstly, not all interventions had control groups, some had more than one component, making it difficult to ascertain to what any improvement should be attributed, and some were based on small participant numbers or a single-case design. Finally, none of the

studies included a longer-term follow-up to see whether the intervention had any lasting effect. Thus at this stage it does not appear that one could reliably draw any firm conclusions from this group of studies. The only observation that does appear to be true of all studies is that none of the interventions have actually been followed by a decline in any aspects of identity, behaviour, well-being, or memory functioning. Some of the strongest effect sizes across studies were seen for interest, pleasure, and involvement (Cohen-Mansfield et al., 2006), which suggests that at the very least, participants enjoyed taking part in the intervention. However, in terms of improvements in functioning, only small effects (if any) were seen for memory, activities of daily living, social behaviour and self care (Romero & Wenz, 2001). It is also difficult to integrate any of these results across studies, given that there is no overlap in the measures used aside from the two studies which both used the Cornell Depression Scale (Haight et al., 2006; Romero & Wenz, 2001). This issue further limits the possibility of being able to draw any firm conclusions from the included studies as a whole.

Discussion

The aim of this review was to identify interventions that have been used to support self or identity in people with dementia, to discuss the main features of these studies, to consider the evidence regarding effectiveness, and to identify possible directions for future research. This is the first review to date to focus specifically on interventions addressing self and identity. Only ten studies met the inclusion criteria for the review, and there was considerable heterogeneity in terms of theoretical conceptualisation, study design, sample characteristics, nature of the interventions, and outcome measurements. The first aim of the review was to identify interventions that have been used to support self and identity in people with dementia. A large number of papers discussed issues relating to self and identity for people with dementia, but despite all the attention devoted to this topic, the development of interventions supporting self or identity in people with dementia seems to be in the early stages, with only ten studies identified. It is particularly interesting that only one life review study and no group reminiscence studies met the inclusion criteria. Certainly in the case of reminiscence therapy, a number of review articles and other papers have documented one of its primary goals as supporting self and identity (e.g.

Coleman, 1986; Coleman, 2005; Downs, 1997; Huang, Li, Yang & Chen, 2009; Woodrow, 1998; Woods, Portnoy, Head & Jones, 1992; Woods, Spector, Jones, Orrell & Davies, 2005). Yet on close examination of reminiscence therapy studies conducted with people with dementia, although issues relating to self or identity may be mentioned, no study specifically identifies supporting self or identity as an aim of the intervention or includes an outcome measure targeting identity. This suggests that although supporting or improving self or identity seems to be viewed as a desirable consequence of such interventions, little attention is actually paid to precisely how this target will be met or how to establish whether it has been met. Interestingly, one recent reminiscence study, which did not meet criteria for this review because participants did not all have a diagnosis of dementia, included two measures of identity (Haslam et al., 2010). There was no statistically significant change in identity in the desired direction in either the group or the individual reminiscence conditions, and the individual reminiscence condition actually led to a decrease in scores on social aspects of self compared to the group reminiscence and control conditions.

The second aim of the review was to discuss the main features of the identified studies. Study quality was generally low, and the extent of heterogeneity makes it very difficult to integrate results. Studies adopted different theoretical conceptualisations and rationales. However there was some convergence in the fact that the vast majority of the interventions relied to some extent on stimulating memory. This is in accordance with the view that a person's sense of self or identity is likely to rely to some extent on memory functioning, especially in relation to autobiographical memory (e.g. Conway, 2005; Conway & Pleydell-Pearce, 2000; Rathbone, Moulin & Conway, 2008; Wilson & Ross, 2003), although other researchers argue against this emphasis on cognition (e.g. Kontos, 2004; Sabat & Collins, 1999; Sabat & Harre, 1992). Some empirical studies with people with dementia have suggested a link between autobiographical memory functioning and aspects of identity (e.g. Addis & Tippet, 2004; Jetten et al., 2010; Mills, 1997) although another study found no such link (Naylor & Clare, 2008). In the present review Massimi et al. (2008) found an improvement in identity without any gains in memory performance, while the excluded study by Haslam et al. (2010) found an improvement in memory performance without an improvement in identity or well-being in their mixed group of older care home residents with and without dementia. Although these results are rather preliminary and based on a small number of

participants, they do suggest that memory, identity, and well-being are not necessarily positively associated with each other. The role of social relationships in maintaining a sense of self and identity was acknowledged through the use of a group approach designed to support or enhance use of social skills or encourage a feeling of belonging (Harlan, 1993; Jensen & Wheaton, 1997), whilst Romero and Wenz (2001) involved relatives of people with dementia in their intervention, on the basis that their behaviour can also enable people with dementia to maintain a sense of self and identity. Sample characteristics also present difficulties with respect to integrating results across studies. In some cases insufficient information was provided regarding stage or severity of dementia (e.g. Harlan, 1993; Jensen & Wheaton, 1997; Johnson et al., 1992), and in two cases there was a wide range of dementia severity (Romero & Wenz, 2001; Yasuda et al., 2006) which made it difficult to determine whether the benefits seen from the intervention occurred for people at all stages of the disease.

The final two aims of the paper were to draw conclusions regarding the effectiveness of such interventions to date, and to highlight implications for future research in this area. Based on the available evidence and taking into consideration methodological limitations and the degree of heterogeneity, it is not possible to derive firm conclusions about efficacy or to make clear recommendations for practice at this time. Further well-designed studies are required to provide robust evidence regarding intervention effects. It would be important to establish the nature of the relationship between key variables such as memory, identity and well-being before designing interventions based upon an assumed relationship between such variables. It is also necessary to consider the desired outcome from such interventions. The aim of the intervention may solely be to support identity, or to support identity with the aim of improving well-being, but as can be seen from the included studies, there are different outcomes that may be affected in different ways and independently of each other. For example Cohen-Mansfield et al. (2006) report improvements in mood and enjoyment following their intervention, but few gains were observed in cognitive functioning, activities of daily living or self-care. Thus it may be important to outline the desired effects more specifically, and to tailor the intervention to these. The range of techniques used in the interventions included in this review also emphasizes the possibilities for the modalities through which future treatments might be presented. The use of art, movement and music are common in treatments for people with dementia (e.g. Harlan, 1993; Johnson et al., 1992; Sherratt et al., 2004; Stewart, 2004;

Wall & Duffy, 2010) although little work has been done to empirically examine whether these types of intervention impact upon identity. In addition, Massimi et al. (2008) demonstrate the possibilities of using technology in a beneficial way to support people with dementia (see Astell, 2006, for a discussion on the use of technology in supporting people with dementia). Further research could investigate the effects of delivering interventions through different modalities to determine what might work best for people with dementia, a diverse group with differing needs, abilities, and preferences. Some of these diverse needs, abilities and preferences may be related to the specific symptoms and disabilities that people with dementia experience, whilst others will have been brought to the situation prior to the onset of dementia simply because every person may be different in these respects.

It is noteworthy that the literature search identified a vast number of studies which also examined self and identity in some way, but which were not intervention studies. These included a number of studies which looked at how identity could be constructed discursively in people with dementia (Adams, 2000; Crichton & Koch, 2007; Saunders, 1998; Surr, 2006; Vittoria, 1998), as well as several studies which examined identity from a narrative viewpoint (Hyden & Orluv, 2009; Page & Keady, 2010; Ryan, Bannister, Anas, 2009). There were also some recent papers regarding more novel approaches to supporting self and identity, including one describing the importance of clothing for maintaining personhood in people with dementia (Twigg, 2010), and another describing the relevance of honouring identity through mealtimes in families living with dementia (Genoe et al., 2010). Two papers described the possibility of participating in support groups or networks for people with dementia, and how this could lead to a 'shared' sense of social identity (Pratt, Clare, & Aggarwal, 2005), by providing opportunities for interactions through which selfhood could be constructed and maintained (Clare et al., 2008). A recent study has also used stimuli based on self-identity roles to engage people with moderate to severe dementia (Cohen-Mansfield, Marx, Dakheel-Ali, Regier, & Thein, 2010; Cohen-Mansfield, Marx., Dakheel-Ali, Regier, Thein, & Freedman, 2010; Cohen-Mansfield, Marx, Thein et al., 2010), demonstrating another possibility for incorporating aspects of self and identity into novel approaches in dementia care. Thus it can be seen that there are many avenues which could be further explored with regard to supporting self and identity in people with dementia, which might have the potential to be incorporated into future interventions aiming to support self and identity.

This review has identified studies aimed at supporting self or identity in people with dementia and discussed the strengths and limitations of these. It is clear that intervention research in this area is in the preliminary stages, and it is thus difficult to draw any robust conclusions from the evidence to date. However, these studies have highlighted the potential of such interventions to support and improve well-being in people with dementia, and suggest that further investigation is warranted.

Chapter 5: A profile of identity in early-stage dementia and a comparison with healthy older people.

Summary

Objectives: The aim of the study was to determine whether people in the early stages of dementia experience their sense of identity differently to healthy older people, and to examine whether different aspects of identity are related to each other in each group.

Method: This was a cross-sectional questionnaire-based study. Fifty people with early-stage dementia and 50 age-matched people without dementia completed measures pertaining to different aspects of identity. Measures of mood and self-esteem were also included so that any differences could be taken into account in the analysis.

Results: There were very few differences in identity between the groups. After differences in levels of anxiety were accounted for, there were no differences in scores on most measures of identity. However, people in the early stages of dementia scored significantly lower on one subtotal for one measure of identity, whereas healthy older adults reported significantly more identity-related distress than people in the early stages of dementia. For both groups there were no associations between different aspects of identity.

Discussion: People in the early stages of dementia do not differ much from healthy older adults in terms of their identity. Since healthy older people experience more distress relating to identity, they may be more likely to benefit from some sort of intervention than people in the early stages of dementia. It might be useful to consider identity as consisting of multiple components in future studies, rather than assuming that one aspect of identity represents the overall experience of identity.

Introduction

The importance of understanding and supporting identity in people with dementia has long been recognised (e.g. Fazio, 2008; Kitwood, 1997), due to the implications for how people cope with the illness, how they relate to others, including friends, family, and health professionals, and what types of intervention might be helpful for them (see Chapter 4). From a research perspective however, this topic has proven to be extremely complex. As a result of the variation in the concepts of identity on which studies are based (Klein, *in press*; Klein & Gangi, 2010), evidence is somewhat disparate and difficult to integrate, and hence it is difficult to draw firm conclusions (see Chapter 2). Another factor that exacerbates this difficulty is that some studies have used measures of self to deduce information about people with dementia without any comparison data from healthy age-matched adults. For example, the Self Identity In Dementia Questionnaire (Cohen-Mansfield et al., 2000) was used to show the deterioration in role-identities in people with dementia, yet without control data it is not possible to determine whether this pattern might also be true of all older people, regardless of the onset of dementia. Studies of identity in healthy older people have not tended to use the same measures as those used in the field of dementia research, so whilst it is acknowledged that processes affecting the stability of identity also occur in aging individuals (e.g. Baltes & Baltes, 1990; Brandstadter & Greve, 1994; Sneed & Whitbourne, 2005), it is not possible to make a direct comparison across groups to see whether identity is affected in the same way in the two groups.

Identity can be defined in many different ways. Models typically encompass a range of elements said to constitute identity. For example, Neisser's (1988) five factor model consists of the 'ecological self', the 'interpersonal self', the 'extended self', the 'private self' and the 'conceptual self'. Within the 'conceptual self' there are a number of components of identity that are of relevance to research with people with dementia, including abstract representations of oneself, such as roles, traits, identity strength, personal characteristics and autobiography (Morin, 2006). Many researchers have explored single aspects of identity in isolation, however, such as role identities (e.g. Cohen-Mansfield et al., 2000), narrative (e.g. Mills, 1997), self-knowledge (e.g. Gil et al., 2001), or self-recognition (e.g. Biringer & Anderson, 1992). One limitation to this approach is that it is difficult to integrate the disparate evidence resulting from these varying definitions of identity and to understand how that particular aspect of

self might relate to other aspects of self. Thus there is an argument for using a comprehensive framework that addresses different possible aspects of identity (see Chapter 3; Klein, in press; Klein & Gangi, 2010). In this study, a number of components that represent Neisser's 'conceptual self' were measured, including strength of identity, direction of identity, role-identities, and self-knowledge of personal characteristics. The relationships between these different aspects of identity were also examined, with the aim of determining whether the self might best be viewed as a unitary construct, or one with a number of separate components. Chapter 3 describes in more detail the argument for using Neisser's model of self to explore identity in people with dementia.

There is evidence to suggest that the onset and progression of dementia affects some of these aspects of identity, including role-identities (Cohen-Mansfield et al., 2000), strength of identity (Addis & Tippet, 2004), and self-knowledge of personality traits (Rankin et al., 2005; Ruby et al., 2009; Ruby et al., 2007), and other work suggests that people with dementia may be left with a view of their identity that is outdated due to an inability to update personal information about the self (e.g. Hehman et al., 2005; Klein et al., 2003; Mograbi, Brown & Morris, 2009). There is also some evidence to suggest that such changes in identity also occur in healthy older adults, such as changes in role-identities (e.g. Elder, 1995; Moen, 1995; Moen, Erickson, & Dempster-McClain, 2000). Ryff (1989) suggested that older people may place less emphasis on self-knowledge compared to younger adults, although the study did not actually assess the accuracy of self-knowledge, and a number of researchers have considered approaches to maintaining a stable sense of identity in old age (e.g. Baltes & Baltes, 1990; Brandstadter & Greve, 1994; Sneed & Whitbourne, 2005). This suggests that even healthy older people experience changes in their sense of identity, so it cannot be assumed that changes in identity experienced in people with dementia are actually attributable to the dementia *per se*.

For both older people in general and for people with dementia, aspects of identity may be linked to mood and well-being. Teri & Reifler (1987) found that approximately 30% of people diagnosed with Alzheimer's disease also meet the criteria for depression. There are also reports that depression is a common problem in older age in people without dementia (Blazer, 1989), with up to 15% experiencing clinically relevant depressive syndromes (Beekman et al., 1995). Anxiety is an issue

that affects older people with and without dementia, with prevalence rates of around 5%-21% for anxiety disorders in people with dementia (Chemerinski, Petracca, Manes, Leiguarda & Starkstein, 1998; Ferretti, McCurry, Logsdon, Gibbons, & Terri, 2001; Forsell & Winblad, 1997; Skoog, 1993) and up to 15% in older people without dementia (Manela, Katona, & Livingston, 1996). Research has also suggested that self-esteem declines in old age (e.g. Robins, Trzesniewski, Tracy, Gosling, & Potter, 2002) and in addition may be a problem for people with dementia, possibly as a result of co-morbid depression (Lopez et al., 2003). Some researchers have suggested that there is a link between mood, well-being and aspects of identity in people with and without dementia (e.g. Berzonsky 2009; George, 1998; Harrison, 1993; Higgins, Klein & Stauman, 1985; Jetten et al., 2010; Ronch, 1996; Thoits, 1983; Vleioras & Bosma, 2005). For this reason it would be valuable to take factors such as mood and self-esteem into account when examining differences in identity between healthy older people and people with dementia, since these variables might affect how a person rates his/her sense of identity.

In summary, older people with and without dementia may experience changes to their sense of identity, and members of both groups may also experience changes in anxiety, depression and self-esteem. This study utilised aspects of identity represented in Neisser's (1988) conceptualisation of the self described earlier, and focused on whether there are any differences in aspects of identity between age-matched people with and without early-stage dementia, and whether such differences remain once mood and self-esteem have been accounted for. Specifically, the research questions were:

- 1) What is the profile of identity in healthy older people and people with early-stage dementia, and are there any differences between the two groups?
- 2) Are there any differences in mood and self-esteem between the two groups?
- 3) Are differences in identity accounted for by differences in mood or self-esteem between the two groups?
- 4) What is the relationship, if any, between the different aspects of identity?

Method

Design

This was a cross-sectional questionnaire-based study, comparing people in the early stages of dementia with healthy older people on measures of identity, to see whether there were any differences in the profile of identity between the two groups, after accounting for levels of mood and self-esteem. Ethical approval was granted by the School of Psychology Ethics Committee and by the North-West Wales NHS Research Ethics Committee (Appendix A).

Participants

Participants were people in the mild stages of dementia (Alzheimer's disease, vascular dementia, or mixed Alzheimer's and vascular dementia) as diagnosed by ICD-10 criteria (WHO, 1992) and 50 age-matched healthy older people without cognitive impairments (according to self-report). Participants with dementia were recruited through two memory clinics and a patient research participation register in North Wales. Inclusion criteria were that participants should be aged 60 or over, in the early stages of dementia as defined by an MMSE score of 18 or above, should be fluent in English, and should have a close relative or friend who was willing to complete several questionnaire measures which required informant ratings. Control participants were recruited through groups in England and North Wales, including University of the Third Age, senior citizen friendship groups, church-based groups, and exercise classes for the over 50s. Inclusion criteria for the control group were a minimum age of 60, fluency in English and availability of a spouse, partner, or close friend who also met inclusion criteria and was willing to participate in the study. All participants were required to be capable of giving informed consent.

Measures

Measures of identity

1) Strength and direction of identity:

Tennessee Self-Concept Scale (2nd Ed) (TSCS-II; Fitts & Warren, 1996). Identity Subscale (Appendix B).

Self-concept was assessed using the 21 items of the TSCS that measure the identity component of self-concept and can be used to calculate a strength of identity score. Each item is rated for self-descriptiveness on a five-point scale from 'always false' to 'always true'. The five domains within this subscale are 'personal', 'family', 'social', 'moral', and 'physical', and are each represented by 3-5 items from the subscale (as used in Addis & Tippet, 2004). The TSCS-II scale also has good internal consistency, test-retest reliability, and construct validity (Coopersmith, 1981; Fitts & Warren, 1996). This scale has been standardised with people from 13 - 90 years of age, making it suitable for use with the participants from this study, and raw scores can be converted to T-scores for comparison with normative data. It has been used successfully with people with dementia (Addis & Tippet, 2004; Naylor & Clare, 2008).

2) Role-identities

Self-Identity in Dementia Questionnaire (Cohen-Mansfield et al., 2000)

This questionnaire explores four types of self-identity roles in people with dementia; occupational roles, family roles, leisure activities and attributes. The questionnaire was designed for use with people with dementia who are in nursing homes, but is also suitable for use with people with and without dementia who live in their own homes. The questionnaire asks about how important each of the four roles were to the person in the past, and how important they are now, on a scale of 1 (not at all) to 5 (very important).

3) Self-knowledge of personality characteristics (Appendix C)

Self and informant ratings of personality traits to measure self-knowledge (40 trait words selected from norms by Anderson, 1968, and Kirby & Gardner, 1972).

Whilst other researchers have successfully used this technique to study trait self-knowledge in people with dementia (Klein et al., 2003; Rankin et al., 2005; Ruby et al., 2007; Ruby et al., 2009), the trait list used was developed specifically for this study. Forty traits were selected from norms (Anderson, 1968; Kirby & Gardner, 1972) to ensure that the adjectives covered the full range of social desirability, and all scored highly on familiarity and meaningfulness. The participant is asked to rate a list of 40 personality traits for how well the adjective describes their own current personality on a scale of 1 (not at all) to 4 (totally). The relative is also asked to rate the list of adjectives for how well they describe the participant's current personality. Discrepancy scores were calculated between participant and informant ratings to allow an assessment of how well the participant ratings of their own traits reflects their current personality. For each item, the difference between the participant's own score and the informant's score was calculated, and then these were totalled to give an overall discrepancy score for all 40 traits. A higher score indicates a greater discrepancy between participant and informant ratings, which is taken to indicate less accurate self-knowledge.

4) Identity-related distress (Appendix D)

Identity Distress Survey (IDS; adapted from Berman, Montgomery, & Kurtines, 2004).

The Identity Distress Survey was originally designed to identify individuals experiencing difficulties in identity maintenance or identity development who met the criteria for 'Identity Disorder' according to the 3rd (revised) edition of Diagnostic and Statistical Manual of Mental Disorders (DSM-III-R; American Psychiatric Association, 1987), although this diagnosis is no longer included in the 4th edition of this diagnostic manual (DSM-IV; APA, 1994). It was used in this study as a measure of current identity distress, after removal of two of the ten items (career choice and sexual orientation) that were considered to be less relevant for older individuals who were mostly retired and many of whom had been married for several decades. Thus the version used was an eight-item self-report questionnaire that measures distress associated with issues regarding identity, including long-term goals, friendships,

religion, values and beliefs, and group loyalties. The scores from these five items were totalled to give a total score for identity distress, which was used in the main analysis. The questionnaire also asks about the overall level of discomfort experienced with respect to these issues, and how much this has interfered with life on the whole. Each of these items is rated on a five-point scale from 1 (not at all) to 5 (very severely). The final question asks how long the respondent has felt upset or worried by these issues, on a scale from 1 (never/less than 1 month) to 5 (more than 12 months). The questionnaire shows good internal consistency and test-retest reliability among young adults (Berman et al., 2004), but to date has not been used with older adults or people with dementia.

Measures of mood and self-esteem

Hospital Anxiety and Depression Scale (HADS; Snaith & Zigmond, 1994)

This is a fourteen-item self report measure that consists of two scales, one for anxiety and one for depression. Each item consists of a statement that must be rated from 0-3, according to how often the statement applies to the respondent. The authors recommended that for both scales, raw scores of between 8 and 10 identify mild cases, 11–15 moderate cases, and 16 or above, severe cases. This measure has shown to be reliable and valid across all age groups (Spinoven et al., 1997) and has been successfully used to measure symptoms of anxiety and depression in people with dementia (Wands et al., 1990).

Rosenberg Self-Esteem Scale (RSE; Rosenberg, 1965)

This is a ten-item self-report measure of global self-esteem. Each item consists of a statement that must be rated on a four-point scale from ‘strongly agree’ to ‘strongly disagree’. Scores from each item are summed to give one overall score for self-esteem. The RSE demonstrates excellent internal consistency and test-retest reliability and demonstrates concurrent, predictive and construct validity (Rosenberg, 1979). The RSE is considered to be an appropriate measure of self-esteem in older people (Breytspraak & George, 1979), and has been used with older people (Duffy and MacDonald, 1990; Krause, 1987) and people with dementia (Burgener, Yang-Yang, Gilbert, & Marsh-Yant, 2008).

Procedure

Participants with dementia and their informants completed the relevant questionnaires at home, with support from the researcher. The measures were completed as part of a wider study on identity in people with dementia, and usually took two visits to complete, although a few participants required more than two visits. Measures were completed in the same order for each participant, with identity-related measures being administered first, to reduce the possibility of other measures affecting a participant's sense of identity. Healthy older control participants and their informants were given the option of completing the measures at home with a researcher present, or having the questionnaires posted out with a return envelope with instructions given both in written format and over the telephone, to ensure that measures were completed correctly and in the desired order. Most healthy older participants chose to have the measures posted out to their houses, and were able to seek clarification from the researcher by telephone if any queries arose.

Data Analysis

Independent samples t-tests were used to detect any significant differences in aspects of identity, mood and self-esteem between healthy older adults and people with dementia. Where a significant difference arose on a given measure, independent samples t-tests were also used to examine item-by-item differences. An ANCOVA was then performed to account for differences in mood or self-esteem, where identified, when comparing people with and without dementia on aspects of identity. Pearson's correlation coefficients were calculated to examine the relationships between the different aspects of identity.

Results

Characteristics of the sample are given in Table 1. The average age was 77.8 years (SD= 7.4, range 60-91) for the people with dementia, and 75.9 years (SD= 6.0, range 60-85) for the healthy older control group. The average MMSE score for people with dementia was 23.7 (SD= 2.7, range 18-29), indicating that participants were in the early stages of dementia. There were no statistically significant differences between

the groups on gender, age, or level of education. There were no significant differences in the PWD group between participants' scores of identity, mood or self-esteem according to marital status, gender, or diagnosis, thus these were treated as one group for the comparison between the PWD and HOC groups (everyone in the HOC group was married, but this was not so in the PWD group).

Table 1. Characteristics of participants by group.

Variable	N		%	
	PWD	HOC	PWD	HOC
Gender (female)	26	25	52	50
Diagnosis				
Alzheimer's disease	38	-	76	-
Vascular dementia	9	-	18	-
Mixed dementia	3	-	6	-
Status				
Married	32	50	64	100
Divorced	3	0	6	0
Widowed	11	0	22	0
Single	1	0	2	0
Co-habiting	3	0	6	0
Children (yes)	44	40	88	80
Education Level				
Secondary	45	38	90	76
College/University	5	12	10	24

Research question 1: What is the profile of identity in healthy older people and people with early-stage dementia, and are there any differences between the two groups?

The mean scores and p-values from the independent samples t-test are shown in Table 2. Scores on the SID show that for both groups, the family role is the strongest, and the occupational role the weakest. Scores for the TSCS Identity subscale total indicated a mean T-score of 45 for healthy older people and 48 for people with dementia. These fell at the 31st and 42nd percentile respectively according to norms for this age group (Fitts & Warren, 1996), suggesting that participants from both groups in this study scored slightly lower than might be expected. Both the self-knowledge

discrepancy scores indicate an average discrepancy of about 0.5 points per trait. With respect to the IDS, the mean scores for either group would not have been sufficient for a diagnosis of Identity Disorder according to DSM-III-R. Scores appear very similar across the two groups, and there was only one significant difference between groups; the HOC group scored significantly higher than the PWD group on measures of identity-related distress. A closer examination of the Identity Distress Survey revealed that healthy older adults scored significantly higher than people with dementia on all types of identity-related distress (long term goals, friendships, religion, values and beliefs, group loyalties; see Table 3), meaning that no single item was responsible for the overall difference in identity distress.

Research question 2: Are there any differences in mood and self-esteem between the two groups?

The mean scores and p-values from the independent samples t-test are shown in Table 4. Scores were similar across the two groups for depression and self-esteem, but there was a significant difference between groups for anxiety, with healthy older people scoring significantly higher than people with dementia. The mean scores for either group do not indicate clinical significance of the symptoms of anxiety or depression, which would have required a score of over 8 points on either scale. However, there were individuals in each group who exceeded the clinical cut-off score of 8 points on either scale. In the dementia group, three people fell into the mild category for anxiety, and one person fell into the severe category. For depression, two people fell into the mild category and two fell into the moderate category. In the healthy older people group, seven people fell into the mild category for anxiety, with two in the moderate category. For depression, four people fell into the mild category.

Research question 3: Are differences in identity accounted for by differences in mood or self-esteem between the two groups?

Due to the differences between the groups in anxiety, an ANCOVA was performed for each identity variable to determine whether there would be any differences between the groups on these identity variables if anxiety was controlled for.

On performing the ANCOVA for each identity variable, with anxiety entered as a covariate, only one change in significance between groups was found. Whereas the scores for the TSCS personal items subtotal were originally not statistically significant at $p < .0038$, the difference became significant after anxiety was controlled for by the ANCOVA [$F(1,93) = 10.52$, $p = .002$, partial eta squared = .102]. The difference in identity distress remained significant, suggesting that this cannot be explained by differences in anxiety between the two groups.

Table 2. Mean scores on identity measures and independent samples t-test results

Measure	HOC			PWD			Min-Max	t	df	p-value
	Mean	SD	Range	Mean	SD	Range				
SID Occupation	3.00	1.56	1.0-5.0	2.82	1.43	1.0-5.0	1.0-5.0	-0.67	98	.55
SID Family	4.56	0.81	1.0-5.0	4.72	0.57	3.0-5.0	1.0-5.0	1.14	98	.26
SID Leisure	4.08	0.79	2.0-5.0	3.74	1.21	1.0-5.0	1.0-5.0	-1.67	97	.10
SID Attributes	4.29	0.65	3.0-5.0	4.06	0.84	1.0-5.0	1.0-5.0	-0.94	96	.17
Average role score	3.96	0.58	2.75-5.0	3.84	0.67	2.25-5.0	1.0-5.0	-0.92	95	.36
TSCS Identity subscale TOT	88.41	14.6	71.0-103.0	90.84	6.54	78.0-104.0	21.0-105.0	1.06	93	.29
Physical items subtotal	20.46	10.75	6.0-23.0	19.96	2.43	15.0-24.0	5.0-25.0	-0.32	95	.75
Moral items subtotal	18.04	1.63	12.0-20.0	18.57	1.62	14.0-20.0	4.0-20.0	1.62	96	.11
Personal items subtotal	21.81	2.30	16.0-25.0	20.67	2.29	14.0-25.0	5.0-25.0	-2.43	94	.02
Family items subtotal	18.25	2.34	11.0-20.0	18.35	2.01	12.0-20.0	4.0-20.0	0.22	95	.83
Social items subtotal	12.92	1.72	8.0-15.0	13.29	1.53	10.0-15.0	3.0-15.0	1.12	96	.27
Personality traits discrepancy	26.15	10.61	12.0-55.0	24.14	7.73	11.0-43.0	0-120.0	-0.95	73	.35
IDS Identity distress total	9.12	2.71	5.0-17.0	6.00	1.34	5.0-10.0	5.0-25.0	-7.24	97	<.001*

Note: SID = Self Identity in Dementia Questionnaire, TSCS = Tennessee Self Concept Scale, IDS = Identity Distress Survey

A Bonferroni correction set the threshold for significance at $p < .0038$.

* $p < .0038$

Table 3. Scores from the individual items on the Identity Distress Survey

Item	HOC			PWD			Min-Max	t	df	p-value
	Mean	SD	Range	Mean	SD	Range				
Q1 Long term goals	1.96	0.99	1.0-4.0	1.44	0.73	1.0-4.0	1.0-5.0	-2.99	98	.004*
Q2 Friendships	2.28	0.98	1.0-5.0	1.30	0.65	1.0-3.0	1.0-5.0	-5.86	98	<.001*
Q3 Religion	1.48	0.76	1.0-3.0	1.02	0.14	1.0-2.0	1.0-5.0	-4.20	98	<.001*
Q4 Values/beliefs	1.44	0.73	1.0-3.0	1.02	0.14	1.0-2.0	1.0-5.0	-3.98	98	<.001*
Q5 Group loyalties	1.90	0.90	1.0-4.0	1.22	0.47	1.0-3.0	1.0-5.0	-4.74	97	<.001*
Total Distress	9.12	2.71	5.0-17.0	6.00	1.34	5.0-10.0	5.0-25.0	-7.28	97	<.001*
Q6 Overall discomfort	2.14	2.03	1.0-5.0	1.52	0.71	1.0-4.0	1.0-5.0	-2.04	98	.04
Q7 Interference with life	1.70	0.84	1.0-3.0	1.24	0.48	1.0-3.0	1.0-5.0	-3.37	98	.001*
Q8 Duration of distress	2.12	1.70	1.0-5.0	2.54	1.92	1.0-5.0	1.0-5.0	1.15	97	.26

A Bonferroni correction set the threshold for significance at $p < .005$.

* $p < .005$

Table 4. Mean scores on measures of mood and self-esteem and independent samples t-test results

Measure	HOC			PWD			Min-Max	t	df	p-value
	Mean	SD	Range	Mean	SD	Range				
HADS Depression	3.45	2.15	0-9.0	3.18	3.08	0-21.0	0-21.0	-0.51	97	.62
HADS Anxiety	5.27	3.13	0-13.0	2.66	3.02	0-21.0	0-21.0	-4.21	97	<.001*
RSE Self-esteem	31.16	5.70	27.0-40.0	29.74	4.04	10.0-40.0	10.0-40.0	-1.41	92	.16

Note: HADS = Hospital Anxiety and Depression Scale, RSE = Rosenberg Self-Esteem Scale

A Bonferroni correction set the threshold for significance at $p < .017$

* $p < .017$

Research question 4: What is the relationship, if any, between the different aspects of identity?

Correlations between the different aspects of identity are shown in Table 5. For both groups, there were no significant correlations between different aspects of identity.

Table 5. Correlations between different aspects of identity

	Av. role identity	TSCS Identity total	Self-knowledge
People with dementia			
Av. role identity	-	-.017	.092
TSCS Identity total	-	-	-.074
Self-knowledge	-	-	-
Healthy older people			
Av. role identity	-	-.034	-.072
TSCS Identity total	-	-	.077
Self-knowledge	-	-	-

A Bonferroni correction set the threshold for significance at $p < .017$

* $p < .017$

Discussion

The aim of this study was to explore whether there were any differences in aspects of identity, mood and self-esteem between healthy older people and people in the early stages of dementia, and whether any such differences in identity remained once mood and self-esteem had been accounted for. The results suggested that the only differences between the groups were that the control group scored more highly on anxiety and identity-related distress, and after the anxiety scores were accounted for, a significant difference emerged between the two groups on the TSCS personal items subtotal.

This study has shown that people in the early stages of dementia do not differ in many aspects of identity from healthy older people, and in fact report fewer signs of identity-related distress and anxiety than age-matched people without dementia. Of the research that has been conducted with people in the earlier stages of dementia, some suggests that identities are being preserved (e.g. Beard, 2004; Fazio & Mitchell, 2009; Gil et al., 2001), whilst other studies note changes in identity (Addis & Tippet, 2004; Ruby et al., 2007). The current study suggests that most aspects of identity do not change in the earlier stages of dementia, or that these changes only occur at the same rate as in healthy older people, thus supporting some previous studies and contrasting with others (see above). Only in one out of 12 identity-related measures and subscales (TSCS personal items subtotal) did people with dementia show a score suggesting a compromised aspect of identity in comparison to healthy older controls, although the actual difference in scores per se was small. Addis and Tippet (2004) found that people with dementia scored lower on the TSCS personal items subtotal than healthy older people, but although this difference was larger than in the current study, it did not reach significance in their study, probably due to the smaller number of participants. They found no significant differences in any other subscales of the TSCS identity scale, which is in accordance with the present study, but they did find a significant difference in TSCS total identity score, which this study did not. However, it is worth noting that the participants in their study had a lower mean MMSE score (19.85) than in this study, which suggests that their participants were further on in the course of dementia than in the current study.

The score on the TSCS personal items subtotal reflects an individual's sense of personal worth and feelings of adequacy as a person, suggesting that people with

dementia might have incorporated some negative aspects of the effects of the disease into their self-concept. Such effects might include symptoms such as changes in cognition (e.g. Reid et al., 1996), or consequences of those symptoms, including limitations regarding activities of daily living (Andersen, Wittrup-Jensen, Lolk, Andersen & Kragh-Sorensen, 2004; Edwards, Baum & Deuel, 1991) and relationships with friends and family (e.g. Magai & Cohen, 1998), for example.

There was also a significant difference between the two groups on the measure of identity-related distress. Further analyses suggested that six out of eight items were significantly different between the two groups, with higher scores (indicating more distress) for healthy older adults. This result is surprising; given the literature indicating the presence of some changes or deterioration in identity in people with dementia (although not to the stage where the self is completely diminished; e.g. Cohen-Mansfield et al., 2000, Cohen-Mansfield et al., 2006; Gillies & Johnston, 2004; Grewal, 1994; Mills, 1997), and the literature relating to healthy older adults, which tends to concentrate on the stability of the self in old age, rather than its decline (e.g. Baltes & Baltes, 1990; Bengtson et al., 1985; Coleman, 1999, Troll & Skaff, 1997), one might expect to find more identity-related distress in people with dementia. Nevertheless, there are several possible explanations for this difference in identity distress. One explanation might be that people with dementia forget, or are unaware of, issues that would otherwise be distressing, such as changes in cognition and consequences related to this. However, a lack of awareness is unlikely to provide a full explanation for this difference, especially since participants were in the early stages of dementia. Although accurate appraisals of functioning may be impaired in some domains, many individuals do show awareness of changes in functioning and abilities (e.g. Clare 2003, 2004, 2010). A further possibility is that people with dementia are unable to update information about the self due to memory deficits, and thus draw on an outdated sense of self when making ratings regarding identity (e.g. Hehman et al., 2005; Klein et al., 2003; Mograbi et al., 2009). If the person with dementia is relying upon an outdated sense of identity then changes might remain undetected, or unregistered, and the person is therefore protected from any potential distress relating to such changes.

Results suggest that in both groups, the aspects of identity are not associated with each other. This suggests that it might be important to consider identity as a construct with multiple components, as recently highlighted by Klein and Gangi

(2010). In light of these results it appears unjustified to conclude that a single aspect of self or identity might reflect the status of self or identity as a 'whole'. It is also possible that if identity is affected in people with dementia or healthy older people at some point, then the different aspects of identity might not all be affected in the same way. It is possible that some aspects of identity might deteriorate whilst others remain stable, although from the current results, it is not possible to determine whether this is the case. In order to address this question empirically it would be necessary to conduct a longitudinal study and measure a number of different components of identity in a population experiencing changes in one or more aspects of identity. Future work tackling this issue could be beneficial in terms of supporting people who are experiencing changes in their sense of identity, if indeed research suggests that this is the case. As described in Chapter 4, most existing interventions aiming to support identity have a single target (e.g. Cohen-Mansfield et al., 2006; Haight et al., 2006; Massimi et al., 2008). Future research may suggest that multi-component interventions targeting several aspects of identity might prove to be a better option.

There are some limitations to this study. Participants received differing levels of support when completing the measures, which could influence the way in which participants responded. Additionally, although the sample was matched for age and education, there were differences in some demographics, for example marital status, which might have affected identity in some way. Of course, these results cannot be generalised to people at different stages of dementia, and further research with people in the more severe stages of dementia would be enlightening in determining whether people with dementia do diverge from healthy older people in terms of maintenance of identity at some point. Longitudinal studies would be of particular value with respect to this. It would also be useful to examine whether other factors such as marital status or social network have an impact on identity in people with dementia, in addition to exploring the reasons for identity distress reported by healthy older people. Finally, the Identity Distress Survey was not designed specifically for this population, thus there is no information regarding the validity of the measure for use with older people with or without dementia. Although participants did not appear to find any of the questions difficult to comprehend or respond to, the items might not necessarily address all of the areas of potential distress for this population. In addition, it might be difficult for people with memory difficulties to respond to the item regarding the timeframe of any reported distress, although participants included in this study did not

appear to struggle with this aspect of the questionnaire. However, it might be more suitable to develop a questionnaire tailored to this population.

In summary, this study has suggested that people in the early stages of dementia do not differ much from healthy older people in various aspects of identity. This both supports and contrasts with aspects of previous literature, which has emphasized both continuity and change in identity in people with dementia. Further work could be undertaken to determine whether a change in identity occurs later on in the course of dementia, and also to explore the root of identity-related distress recorded in healthy older people. This would help health professionals to provide the most appropriate support and care for older people with and without dementia.

Chapter 6: How does identity relate to cognition and functional abilities in early-stage dementia?

Summary

Objectives: The aim of the study was to investigate the relationships between identity and cognitive and functional abilities in people with early-stage dementia.

Method: Fifty people in the early stages of dementia completed measures of identity and cognitive and functional abilities, including autobiographical memory. Multiple regression analyses were used to determine whether it was possible to predict any of the variance in identity from cognitive and functional abilities, or from autobiographical memory alone.

Results: It was possible to predict approximately a quarter of the variance in two out of three aspects of identity from cognitive and functional abilities. The relationships between aspects of identity and autobiographical memory functioning were very weak.

Discussion: The relationship between identity and cognitive and functional abilities is not straightforward. There is no evidence to suggest a linear relationship between an overall decline in cognitive functioning and a deterioration in identity.

Introduction

Whether or not identity is dependent upon cognitive abilities in people with dementia is a much-debated issue. Many are reluctant to accept this notion due to the implications for the person with dementia, whose identity would be viewed as deteriorating alongside cognitive abilities. However, to date there is no comprehensive study focusing on the possible relationships between identity and aspects of cognitive functioning, with the exception of several studies relating identity to memory functioning (e.g. Addis & Tippet, 2004; Jetten et al., 2010; Naylor & Clare, 2008). This study aims to address this gap in the literature, focusing on different aspects of cognitive functioning and drawing on a widely cited conceptual framework of the self (Neisser, 1988).

One of the most salient issues in researching identity is how one chooses to define it. In dementia research, identity has previously been defined in a variety of ways, usually involving only a single component such as role-identities or self-knowledge (e.g. Cohen-Mansfield et al., 2000; Gil et al., 2001), and this has proven to be problematic in terms of integrating evidence. As a result of this, a strong argument has been put forward to consider the possibility that identity may be made up of a number of components and to use a comprehensive theoretical framework that reflects this in future research (see Chapter 3; Klein & Gangi, 2010). Chapter 3 describes how Neisser's (1988) model of the self might be useful in this respect. Neisser's model of self consists of five different 'selves' that are distinct from each other, but which interact in such a way that individuals experience a unified self. The final component of self is the 'conceptual self', which represents a tying together of the other four components of self and includes aspects of identity such as strength and direction of identity, role identities, and self-knowledge of personality characteristics, which will each be measured in this study. Since there is evidence that some of these aspects of identity are affected in people with dementia (e.g. Addis & Tippet, 2004; Cohen-Mansfield et al., 2000; Jetten et al., 2010; Klein et al., 2003), it is possible that declining cognitive abilities play some part in this change.

This study focuses specifically on people in the early stages of dementia, and the cognitive abilities that are likely to be compromised in this population (e.g. Reid et al., 1996). The potential links between cognitive functioning and identity have been considered only to a limited extent, primarily focusing on the theoretical reasons for a

link between memory (particularly autobiographical memory) and identity, which has been investigated in people with dementia (e.g. Addis & Tippet, 2004; Jetten et al., 2010; Naylor & Clare, 2008). Conway and Pleydell-Pearce (2000) describe the Self-Memory System (SMS), which consists of a working self and a knowledge base that can interact to form a system that allows autobiographical remembering to occur. There is a reciprocal relationship between the working self and autobiographical knowledge, whereby if autobiographical memory is impaired, then the self and its working goals would also be influenced. Klein, German, Cosmides and Gabriel (2004) regard autobiographical memory as central to defining oneself due to the ability to mentally travel through time to relive previously experienced events (Tulving, 1993, 2002). These events are remembered as belonging to the self, and thus the self becomes defined by such memories. Other studies have examined the role of semantic and episodic memory in self-knowledge (e.g. Klein, Loftus, Trafton & Fuhrman, 1992; Klein, Rozendal, & Cosmides, 2002). Two models have been put forward to explain the formation of self-knowledge; the computational view, which argues that we need to retrieve memories of trait-relevant behaviours in order to judge how similar these are to the trait being judged, and the abstraction view, which suggests that summary representations based on these memories have already been formed and can be accessed (Klein et al., 2002). Klein et al. (1992) suggest that both models are used in conjunction with each other. This view of the acquisition of trait self-knowledge (particularly the computational model) would suggest a possible mechanism by which one might expect people with memory impairment, such as those with dementia, to fail to retain up to date information about aspects of their self. Indeed, some studies have found that self-knowledge appears to be out of date in people with dementia (Klein et al., 2003), particularly early-stage fronto-temporal dementia, whilst it appears that people with early-stage Alzheimer's disease might be as accurate as healthy participants at rating their current personality (Rankin et al., 2005; Ruby et al., 2009; Ruby et al., 2007). Due to the particular focus on the relationship between identity and autobiographical memory in existing literature, this study will explore the relationships between traditional memory tests and identity (including word list learning, immediate and delayed recall and recognition tasks), and autobiographical memory tests and identity separately.

Other work concerns the relationships between identity and other cognitive abilities, including language abilities, executive functioning and praxis. Hart (1988)

describes possible language impairments in people with dementia, including naming and word fluency. There is a body of literature describing the importance of language in establishing social identity (e.g. Eastman, 1985; Hansen & Liu, 1997), suggesting that for some people with dementia, constructing a social identity could be challenging. Some work with people with dementia focuses on how identity is created through interactions with others, such as the social constructionist (e.g. Fazio & Mitchell, 2009; Sabat, 2002; Sabat & Collins, 1999; Sabat & Harre, 1992; Small et al., 1998; Tappen et al., 1999) and interactionist models (e.g. Fontana and Smith, 1989; Hubbard et al., 2002; Saunders, 1998), which would rely to a great extent on language functioning. Executive functioning may also be impaired in people with dementia, including Alzheimer's disease (Collette, Van der Linden, & Salmon, 1999). This includes a number of impairments that all come under the umbrella term of 'executive functioning', including fluency tasks (e.g. Henry, Crawford & Phillips, 2004) and planning abilities (e.g. Mack & Patterson, 1995; Rainville, Fabrigoule, Amieva, Lafont, & Dartigues, 1998). It has been suggested that executive functioning is involved in self-regulation (Baumeister, Schmeichel & Vohs, 2007; Vohs & Schmeichel, 2007), a quality which allows people to inhibit behaviours that would put them at risk of personal or social problems (Baumeister, 2002), such as social exclusion (Heatherton, 2011), which in turn could affect a person's sense of identity. Another strand of research has examined the influence of executive functioning on activities of daily living, with several studies finding that executive functioning was associated with impaired activities of daily living (e.g. Cahn-Weiner, Boyle & Malloy, 2002; Jefferson, Paul, Ozonoff, & Cohen, 2006). Work on constructional apraxia in people with dementia has suggested that deficits in this domain could also lead to impaired activities of daily living. Edwards et al., (1991) found a relationship between constructional apraxia and activities of daily living in their study with people with Alzheimer's disease. Although no work has been undertaken on this topic, it is possible that such impairments in executive functioning and praxis could also extend to abilities or roles that might have the potential to affect a person's sense of identity. For example, relying on relatives for support with such activities could affect the quality of the relationship (e.g. Magai & Cohen, 1998), impacting on the person's identity.

Thus evidence regarding the relationships between different cognitive functions and aspects of identity is limited, but suggests that it is likely that there will

be some associations between cognitive functioning, functional activities, and identity in people with dementia. In light of this, the aims of the study are:

1. To explore associations between aspects of identity and aspects of cognitive and functional abilities.
2. To determine whether it is possible to predict variance in aspects of identity from aspects of cognitive and functional abilities.
3. To explore associations between aspects of identity and autobiographical memory functioning.
4. To determine whether it is possible to predict variance in aspects of identity from autobiographical memory functioning.

Method

Design

This was a cross-sectional study, examining the relationships between identity and aspects of cognitive functioning in people with early-stage dementia. Ethical approval was granted by the School of Psychology Ethics Committee and by the North-West Wales NHS Research Ethics Committee (Appendix A)

Participants

Participants were people in the mild stages of dementia (Alzheimer's disease, vascular dementia, or mixed Alzheimer's and vascular dementia) according to ICD-10 criteria (WHO, 1992). Participants were recruited through two local memory clinics and also through a patient research participation register (NEURODEM) in North Wales. Inclusion criteria were that participants should be aged 60 or over, in the early stages of dementia as defined by an MMSE score of 18 or over, and should be fluent in English.

Measures

Measures of identity

1) Strength of identity

Tennessee Self-Concept Scale (2nd Ed) (TSCS-II; Fitts & Warren, 1996). Identity Subscale (Appendix B)

The TSCS identity subscale was used to assess strength of identity. This consists of 21 items, which each are rated for self-descriptiveness on a 5 point scale from 'always false' to 'always true', with a higher total score indicating a stronger sense of identity. This scale has been standardised with people from 13 - 90 years of age, making it suitable for use with the participants from this study, and raw scores can be converted to T-scores for comparison with normative data. The TSCS-II scale also has good internal consistency, test-retest reliability, and construct validity (Coopersmith, 1981; Fitts & Warren, 1996) and has also been used successfully with people with dementia (Addis & Tippet, 2004; Naylor & Clare, 2008).

2) Role-identities

Self-Identity in Dementia Questionnaire (Cohen-Mansfield et al., 2000)

This questionnaire explores four types of self-identity roles in people with dementia; occupational roles, family roles, leisure activities and attributes. There are separate versions for the person with dementia, a close family member, and a staff caregiver. Only the version for the person with dementia was used in this study. This asks about how important each of the four roles are currently, on a scale of 1 (not at all) to 5 (very important). For the purpose of this study a mean score of the four role-identity scores was calculated.

3) Self-knowledge of personality characteristics (Appendix C)

Self and informant ratings of personality traits to measure self- knowledge (40 trait words selected from norms by Anderson, 1968, and Kirby & Gardner, 1972).

Ratings of personality traits have been used by several researchers to study trait self-knowledge in people with dementia (Klein et al., 2003; Rankin et al., 2005; Ruby et al., 2007), but the trait list used here was developed specifically for this study. Forty traits were selected from norms (Anderson, 1968; Kirby & Gardner, 1972) to ensure

that all adjectives scored highly on familiarity and meaningfulness, and spanned the full range of social desirability. The participant is asked to rate a list of 40 personality traits for how well the adjective describes their own current personality on a scale of 1 (not at all) to 4 (totally). The relative is also asked to rate the list of adjectives for how well they describe the participant's current personality, on a parallel scale. The difference between the participant's own score and the informant's score is calculated for every item, and then these are totalled to give an overall discrepancy score for all 40 traits. A higher score indicates a greater discrepancy between participant and informant ratings, which is taken to indicate less accurate self-knowledge.

Measures of cognitive and functional abilities

CERAD battery (Morris, Heyman, Mohs, Hughes, van Belle, Fillenbaum et al., 1989)

This is a brief neuropsychological battery developed to assess people with dementia or suspected dementia on measures of language, memory, and praxis. It consists of the Mini Mental State Examination (Folstein et al., 1975; see above) in addition to 6 other measures:

- 1) a modified Boston naming test
- 2) a verbal fluency test (number of unique responses)
- 3) accuracy of design copy (constructional praxis)
- 4) immediate recall of word list
- 5) delayed recall from word list task and constructional praxis task
- 6) recognition memory for word list task

Autobiographical Memory Interview (AMI; Kopelman et al., 1990)

The AMI is a structured interview that measures both personal semantic and personal incident memory across three lifetime periods: childhood (Section A), early adult life (Section B), and recent adult life (Section C). Personal semantic memory assesses a participant's recall of personal facts such as the different addresses he/she has lived at, whereas personal incident memory assesses the recall of specific incidents of the participant's choosing and requires access to episodic memory. This measure provides a total semantic memory score and a total incident memory score, in addition to semantic and incident memory scores for each of the three lifetime periods. The AMI is suitable for use with older people (Kopelman et al., 1990), and has been

successfully used with people with dementia in previous studies (Addis & Tippet, 2004; Naylor & Clare, 2008).

Functional Activities Questionnaire (FAQ; Pfeffer, Kurosaki, Harrah, Chance, & Filos, 1982)

This is an eleven-item questionnaire that assesses performance on functional activities in older adults in the community. Each item is rated on a scale from 0-3, according to whether the participant is able to perform the activity independently, independently but with difficulty, with assistance, or is completely dependent on another person to perform the activity for them. Responses are summed across items to give an overall score for performance on functional activities. A lower score indicates a greater degree of independence. The FAQ was designed for use with older adults, and has been used frequently to assess people with dementia (e.g. Herrera, Caramelli, Silveira, & Nitrini, 2002; Juva et al., 1997).

Procedure

Participants and informants completed the measures at home, with support from the researcher. This forms part of a wider study on self and identity in people with dementia, where participants were usually able to complete the measures in two visits, although several participants took up to five to complete all measures. Participants completed measures in the same order, with the identity-related questionnaires completed first so that the other measures would not have an impact on how identity was rated.

Data analysis

Bi-variate correlations were used to examine relationships between scores on measures of identity and scores on aspects of cognitive and functional abilities. Following this, three multiple regression analyses were performed with each aspect of identity entered as the dependent variable in one regression, to see whether aspects of identity can be predicted by aspects of cognitive and functional abilities. Following the same format, correlations were used to examine relationships between scores on measures of identity and scores on autobiographical memory functioning, then a

further three multiple regression analyses were performed to see whether aspects of identity could be predicted by aspects of autobiographical memory functioning. Backward regression with the removal probability of $p > .10$ was used in SPSS v 15, with the predictors selected according to the variables that were most highly correlated with each aspect of identity. The stopping criterion used was the model with the highest adjusted R_a^2 value. In line with recommendations that suggest there should be at least 10 participants per predictor variable (e.g. Stevens, 1986), no more than four predictor variables were entered into each regression (although there were 50 participants, a small amount of missing data meant that the number of complete data sets in each analysis was slightly less than 50).

Results

Characteristics of the sample are given in Table 1. The average age for the sample was 77.8 years ($SD = 7.4$, range = 60-91), and the mean MMSE score was 23.7 ($SD = 2.7$, range = 18-29), indicating that participants were in the mild stages of dementia. There were no significant differences on measures of identity or cognitive and functional abilities according to gender, marital status, or diagnosis.

Table 1. Characteristics of participants

Variable	N	%
Gender (female)	26	52
Diagnosis		
Alzheimer's disease	38	76
Vascular dementia	9	18
Mixed dementia	3	6
Status		
Married	32	64
Divorced	3	6
Widowed	11	22
Single	1	2
Co-habiting	3	6
Children (yes)	44	88
Education Level		
Secondary	45	90
College/University	5	10

Research question 1: Are there associations between aspects of identity and cognitive and functional abilities?

Table 2 shows the means, SDs and ranges for the identity-related measures. The mean raw score on the TSCS represented a T-score of 48 and fell within the 42nd percentile with respect to the normative data (Fitts & Warren, 1996), suggesting that the scores were possibly slightly lower than might have been expected for people of the same age without dementia. The role-identity with the highest score was the family role, with the occupational role scoring the lowest, which is in line with the fact that all participants were retired at the time of the study. The self-knowledge mean score reflected a reasonable level of accuracy, with an average discrepancy of less than one point per item.

Table 2. Scores on measures of identity

	N	Mean	SD	Range	Min-Max
TSCS Identity scale total	49	90.84	6.54	78.0-104.0	21.0-105.0
SID Occupational importance	50	2.82	1.45	1.0-5.0	1.0-5.0
SID Family importance	50	4.72	0.57	3.0-5.0	1.0-5.0
SID Leisure importance	50	3.74	1.21	1.0-5.0	1.0-5.0
SID Attributes importance	49	4.06	0.94	1.0-5.0	1.0-5.0
SID mean score	49	3.84	0.67	2.25-5.0	1.0-5.0
Self-knowledge	42	24.14	5.65	11.0-43.0	0-120.0

Table 3 shows the means, SDs and ranges for the cognitive and functional abilities.

On the CERAD, the verbal fluency, word list 3 recall, and word list delayed recall scores fell within the poorest 5% of scores according to available normative data, suggesting impairments in these domains of functioning in this sample. The CERAD naming and constructional praxis scores did not fall into the poorest 5%, which probably indicated more variability within the participant group on these tasks. However, these scores were still low, and overall this profile of scores is consistent with expected impairments in people with a diagnosis of dementia. The mean FAQ score also fell into the impaired range, which is indicated by a total score of over 9 points (Pfeffer et al., 1982), although the range shows that not all participants fell into the impaired range on this measure.

Table 3. Scores on measures of cognitive and functional abilities

	N	Mean	SD	Range	Min-Max	Percentile*
CERAD verbal fluency	49	10.43	5.05	2.0-27.0	0- no max	2
CERAD naming	49	12.57	2.02	7.0-15.0	0-15.0	8
CERAD constructional praxis	48	8.54	2.69	0-11.0	0-11.0	13
CERAD word list learning trial 3	47	4.43	1.98	0-9.0	0-10.0	<1
CERAD word list direct recall	47	1.34	1.87	0-7.0	0-10.0	<1
CERAD word list recognition	46	15.72	3.54	0-20.0	0-20.0	-
CERAD constructional praxis recall	47	2.91	2.77	0-12.0	0-14.0	-
FAQ	50	9.84	6.99	0-31.0	0-33.0	N/A

* The percentile column shows within which percentile the mean score of the CERAD subscale fell according to norms based on people of the same age without dementia (where normative data is available; Welsh et al., 1994)

Bivariate correlations between the aspects of identity and cognitive and functional abilities are shown in Table 4. No correlations reached significance after the Bonferroni correction.

Table 4. Bivariate correlations between measures of identity and measures of cognitive and functional abilities

	TSCS Ident. Tot.	SID mean	Self- knowledge
CERAD verbal fluency	.038	.046	.075
CERAD naming	.211	-.225	.296
CERAD constructional praxis	.267	.244	-.006
CERAD word list learning trial 3	.013	.047	.288
CERAD word list direct recall	-.035	.105	.179
CERAD word list recognition	-.163	.375	.186
CERAD constructional praxis recall	-.355	.132	.050
FAQ	-.319	-.054	.170

The Bonferroni correction set the threshold for significance at $p < .0021$

*significant at $p < .0021$

Research question 2: Is it possible to predict variance in aspects of identity from cognitive and functional abilities?

A backward regression was conducted with each of the identity-related variables as the dependent variable. The results are shown in Table 5. The predictors entered were based on the correlation size between the variables as given in Table 4, such that the cognitive functioning/ functional ability variables with the highest correlations with the identity variables were entered as predictors. The stopping criterion used was the highest R_a^2 value for each model.

Table 5. Backward regression analyses predicting aspects of identity from cognitive and functional abilities

	TSCS Ident Tot		SID Mean score		Self- knowledge	
R_a^2 for model	.240		.254		-	
	β	p	β	p	β	p
CERAD verbal fluency						
CERAD naming	.255	.083	-.328	.019	*	
CERAD constructional praxis	.168	.220	.277	.040		
CERAD word list learning trial 3					*	
CERAD word list direct recall					*	
CERAD word list recognition			.432	.002	*	
CERAD constructional praxis recall	-.415	.004	*			
FAQ	-.191	.186				

* indicates a variable that was entered into the regression but did not remain in the model.

Strength of identity was significantly predicted by a model containing CERAD naming, constructional praxis and constructional praxis recall scores, and the FAQ total score ($F_{4,41} = 4.557$, $p < .01$, $R_a^2 = .240$), with just the CERAD constructional praxis recall score being individually significant. A higher strength of identity score was predicted by higher CERAD naming and constructional praxis scores, and lower CERAD constructional praxis recall and FAQ total scores.

The role identity mean score was significantly predicted by a model containing CERAD naming, constructional praxis, and word list recognition scores

($F_{3,41} = 6.00$, $p < .01$, $R_a^2 = .254$), with all scores being individually significant. A higher role identity mean score was predicted by higher CERAD constructional praxis and word list recognition scores, and a lower CERAD naming total score. The CERAD constructional praxis recall score was entered into the regression but did not remain in the final model.

It was not possible to predict the self-knowledge score from a model containing scores relating to cognitive and functional abilities.

Research question 3: Are there associations between identity and autobiographical memory functioning?

Table 6 shows the mean, SD and range for the autobiographical memory variables. For both personal semantic and autobiographical incident subscales the scores showed a temporal gradient, with lower scores for more recent memory items, as would be expected for people with dementia. Both the personal semantic and autobiographical incident total scores fell within the ‘definitely abnormal’ range based on normative data from healthy older people (Kopelman et al., 1990).

Table 6. Scores on the Autobiographical Memory Interview

	N	Mean	SD	Range	Min-Max
Personal Semantic Sect. A	49	14.87	4.74	1.0-21.0	0-21.0
Personal Semantic Sect. B	49	14.81	4.57	4.5-21.0	0-21.0
Personal Semantic Sect. C	49	13.45	5.28	0.5-20.5	0-21.0
Autobiographical Incident Sect. A	49	3.81	2.58	0-9.0	0-9.0
Autobiographical Incident Sect. B	49	3.67	2.32	0-8.0	0-9.0
Autobiographical Incident Sect. C	49	2.67	1.92	0-7.0	0-9.0
Personal Semantic Sect. TOT	49	43.12	12.54	13.0-62.5	0-63.0
Autobiographical Incident TOT	45	10.16	5.65	1-23.0	0-27.0

Bivariate correlations between the aspects of identity and autobiographical memory functioning are shown in Table 7. No correlations reached significance after the Bonferroni correction.

Table 7. Bivariate correlations between measures of identity and autobiographical memory functioning.

AMI	TSCS Ident. Tot.	SID mean	Self- knowledge
Personal Semantic Sect. A	-.077	.175	.109
Personal Semantic Sect. B	-.093	.237	.065
Personal Semantic Sect. C	-.102	.148	.216
Autobiographical Incident Sect. A	.166	.253	.043
Autobiographical Incident Sect. B	-.089	.089	.052
Autobiographical Incident Sect. C	-.087	.268	-.026
Personal Semantic Sect. TOT	-.104	.157	.140
Autobiographical Incident TOT	-.004	.303	.037

A Bonferroni correction set the threshold for significance at $p < .0021$

*significant at $p < .0021$

Research question 4: Is it possible to predict aspects of identity from autobiographical memory functioning?

A backward regression was conducted with each of the identity-related variables as the dependent variable. The predictors entered were based on the correlation size between the variables as given in Table 7, such that the autobiographical memory variables with the highest correlations with the identity variables were entered as predictors, with a maximum of four entered for each regression. The stopping criterion used was the highest R_a^2 value for each model.

Table 8. Backward regression analyses predicting aspects of identity from autobiographical memory functioning

	TSCS Ident		SID Mean		Self-	
	Tot		score		knowledge	
R_a^2 for model	-		.072		-	
	β	p	β	p	β	p
Personal Semantic Sect. A					*	
Personal Semantic Sect. B	*		*		*	
Personal Semantic Sect. C	*				*	
Autobiographical Incident Sect. A	*		*			
Autobiographical Incident Sect. B						
Autobiographical Incident Sect. C			*			
Personal Semantic Sect. TOT	*				*	
Autobiographical Incident TOT			.303	.036		

* indicates a variable that was entered into the regression but did not remain in the model.

The role identity mean score was significantly predicted by a model containing the AMI autobiographical incident total score ($F_{1,46} = 4.647$, $p < .05$, $R_a^2 = .072$). A higher role identity mean score was predicted by a higher AMI autobiographical incident total score, but this only accounted for a small percentage of the variance. It was not possible to predict the TSCS identity total score or the self-knowledge score from a model containing aspects of autobiographical memory performance.

Discussion

The aim of this study was to investigate potential links between aspects of identity and cognitive and functional abilities in people with early-stage dementia. Results suggest that there are associations between aspects of identity and cognitive and functional abilities, and that some of the variance in aspects of identity can be explained by these abilities. Some of the predictors in the regression analyses occurred in the expected direction, such that improved cognitive and functional abilities predicted higher scores on aspects of identity (or a lower score on self-knowledge, which would indicate more accurate self-knowledge). More unexpectedly, some associations suggested that lower scores on certain aspects of cognitive abilities predicted higher scores on measures of identity. There is also a large proportion of the variance that cannot be explained by these variables, suggesting that other factors also have an influence on identity in people with dementia.

The only significant predictor for a stronger sense of identity was a lower score on the constructional praxis recall task, although the naming score was approaching significance, with higher scores predicting a stronger sense of identity. Naming abilities are likely to impact upon an individual's communications with others, with poor language abilities affecting everyday conversation. In turn, this could potentially affect relationships with friends and family and the ability to interact with others, as indicated by previous work with people with dementia (Fazio & Mitchell, 2009; Fontana & Smith, 1999; Hubbard et al., 1992; Sabat, 2002; Sabat & Collins, 1999; Sabat & Harre, 1992; Saunders, 1998). Thus if interactions are impaired by difficulties with conversational exchanges, it is likely that identity might be adversely affected. It is difficult to explain why a lower memory recall score (whether on the constructional praxis task or otherwise) would promote a stronger sense of identity. This finding runs counter to the literature that suggests a positive association between memory abilities and a sense of identity (e.g. Conway and Pleydell-Pearce, 2000; Klein et al., 2004; Klein et al., 1992; Klein et al., 2002). One possibility is that the relationship between memory and identity might be mediated by awareness of memory functioning. One study found that lower awareness of memory functioning is associated with lower memory performance on autobiographical incident memory (for the mid-life period), and with higher ratings of self-concept

(Naylor & Clare, 2008). However, it would be necessary to conduct further research to determine whether this is the case.

Significant predictors for an increased importance of role-identities suggest that higher constructional praxis and word list recognition scores are salient factors in maintaining role identities, alongside lower scores on naming. A higher constructional praxis score could reflect an improved ability to partake in activities of daily living (Edwards et al., 1991). This could impact upon identity in at least two ways - it might allow the person to participate in activities which could support identity (e.g. Gitlin, Winter, Burke, Chernett, Dennis, & Hauck, 2008), and it might also mean that since functional abilities are greater, caregivers are less affected by the strain of caring for the person with dementia, which might avoid a deterioration in the relationship. This in turn might support a person's identity. Research has suggested that improved activities of daily living are linked to lower caregiver burden and a better quality of relationship (e.g. Magai & Cohen, 1998), and there is a lot of work with people with dementia which emphasizes the role of others in supporting the person's sense of identity, as described above. Improved memory might allow a person to maintain past role identities, such as the occupational role. Although for many, the most salient role identity might relate to current roles such as relationships and leisure activities, for some people past roles might still be of importance (e.g. Cohen-Mansfield et al., 2000), and maintaining these roles might be beneficial for a person's identity. Again, it is difficult to explain how a lower score on the naming task might lead to a higher score on the importance of role-identities, especially since a higher score on this task predicted a stronger sense of identity on the TSCS, as described earlier.

It was not possible to significantly predict self-knowledge from scores relating to cognitive and functional abilities. It is surprising that no memory tasks were significant predictors of self-knowledge, since both the abstraction and the computational view of self-knowledge are thought to rely on memory abilities (Klein et al., 1992; Klein et al., 2002). Also surprising, in the light of existing literature, was the extent to which autobiographical memory appeared to be unrelated to the aspects of identity. This supports previous studies to some degree. Naylor & Clare (2008) found no relationship between identity and autobiographical memory in people with dementia, and Addis & Tippet (2004) only found a very small number of significant associations between aspects of identity and autobiographical memory. However, this is counter to the theoretical literature, which suggests a strong link between

autobiographical memory and identity (e.g. Conway and Pleydell-Pearce, 2000; Klein et al., 2004). This discrepancy between theory and evidence suggests that perhaps further research needs to be conducted whereby certain types of autobiographical memory (such as self-defining memories, e.g. Blavog & Singer, 2004) or different aspects of identity are considered. This finding also has implications regarding potential interventions targeting identity in people with dementia. To date, most interventions have focused on reinforcing autobiographical memories with the aim of supporting identity (see Chapter 4), but these results suggest that this technique might be of limited benefit.

Although it is possible to make connections between better functioning on the cognitive tests and an improved sense of identity, results which suggest that worse functioning on certain cognitive tests is associated with an improved sense of identity indicate that there is no straightforward relationship between cognitive functioning in general and identity - the picture that emerges from this study suggests a much more complex relationship between cognitive and functional abilities and identity, which might vary across different aspects of identity. It is possible that where people score particularly badly on one measure of cognitive functioning that might interfere with the maintenance of one aspect of identity, more effort might be put into maintaining other aspects of cognitive functioning that are still intact and might support other aspects of identity. For example, somebody who scores poorly on one measure of cognitive functioning, such as memory, might deliberately rely more on another aspect of cognitive functioning, such as intact communication or functional abilities, to partake in social and leisure activities that support identity. Alternatively, people who struggle with communication skills might put more effort into participating in activities that do not rely upon these skills, such as certain role-identities (e.g. some leisure activities). This would support the work of Baltes and Baltes (1990) who put forward their model of selective optimization with compensation, which is a general model of adaptation used by healthy older people. The basic premise of this model is that when losses are encountered, selection, compensation, or optimisation processes are activated, such that people select goals that are particularly important to them and concentrate on maintaining such activities.

There were also some limitations of the current study. Firstly, only people in the mild stages of dementia participated, meaning that the results cannot be generalised to people in the more severe stages of the disease. Secondly, it might have

been helpful to use more than a single measure for some cognitive abilities. Whilst verbal fluency, for example, is generally viewed as a reflection of executive functioning (e.g. Kemper & McDowd, 2008), this is a complex ability that would be more accurately represented by administering a number of different tasks. Further research should take these limitations into account.

Overall, this study challenges the notion that identity is directly related to cognitive functioning, at least in people with early-stage dementia. Even where the relationships are in the expected direction, no more than approximately one quarter of the variance is explained by cognitive functioning for each of the aspects of identity, suggesting that many other factors may also play a role in the maintenance of identity. It is interesting that constructional praxis and functional activity scores were both related to higher scores on aspects of identity. Both potentially reflect improved activities of daily living (Edwards et al., 1991), which suggests that it might be what people with dementia do, rather than what they remember, that supports identity. Further studies could look more closely at the relationship between identity and activities of daily living, leisure activities and social networks, which might also account for some of the variance in aspects of identity.

Chapter 7: Identity, mood and quality of life in people with early-stage dementia

Summary

Objectives: The aim of the study was to explore the relationship of identity with mood and quality of life in the people in the early stages of dementia.

Method: This was a cross-sectional questionnaire-based study. Fifty people in the early stages of dementia completed measures pertaining to different aspects of identity, mood and quality of life. Multiple regression analyses were carried out to determine whether it was possible to predict any of the variance in mood and quality of life from aspects of identity.

Results: It was possible to predict 12.8% of the variance in anxiety, 23.4% of the variance in depression, and 25.1% of the variance in quality of life from different aspects of identity. Predictors varied for each dependent variable.

Discussion: Aspects of identity predict a modest proportion of the variance in anxiety, depression and quality of life. This suggests that supporting identity in people with dementia who are experiencing difficulties in this regard might have a positive impact on mood and quality of life. However the majority of the variance in mood and quality of life must be accounted for by other variables.

Introduction

The topic of identity maintenance or loss in people with dementia is the subject of much debate amongst researchers. Initial reports claimed that the self of people with dementia was lost as the disease progressed, and were often accompanied by descriptions of the unwelcome effects of this deterioration in the self, such as horror, anxiety, fearfulness and isolation (e.g. Cohen & Eisdorfer; 1986; Fontana & Smith, 1989; Herskovits, 1995). However, recent literature regarding identity in people with dementia contradicts earlier research and suggests that self and identity are often maintained through to the later stages of disease (see Chapter 2). Although a number of researchers have suggested that it might be important to support the identity of people with dementia due to the potential impact on different aspects of their lives, such as quality of life and mental health (e.g. Droes et al., 2006; Fazio, 2008; George, 1998; Ronch, 1996), there is little empirical research to highlight the associations between identity and such variables. In light of this gap in the literature, the aim of this study is to gain an understanding of how different aspects of identity are related to mood and quality of life in people with early-stage dementia.

A major difficulty with existing studies focusing on identity in people with dementia is that studies tend to rely on different definitions or frameworks of identity (see Chapters 2 & 3). This makes it difficult to draw firm conclusions from existing studies, since the variety of definitions and frameworks used means that many studies, including those focusing on interventions, are aiming to explore or support different aspects of identity. It is therefore difficult to deduce whether identity might consist of more than one component, and if so, how these components might be related. For this reason, several researchers have suggested that it might be beneficial to view identity as being made up of several components (Chapter 3; Klein, in press; Klein & Gangi, 2010). For this study, as discussed in Chapter 3, the definition of identity adopted was based upon Neisser's (1988) framework of the self. Neisser's view of the self is that it consists of a number of components, which can be considered to be hierarchical. The final component, the 'conceptual self' draws on the other four components, which interact to form several aspects of identity. These include strength and direction of identity, role-identities, self-knowledge of personality, and autobiographical memory, which were all measured in the current study.

Much attention has also been paid to possible changes in mood and quality of life in people with dementia. Existing literature relating to anxiety and depression in people with dementia is extensive. A recent review of the literature reported that prevalence estimates for anxiety range from 5-21% for anxiety disorders and from 8-71% for symptoms of anxiety in people with dementia, and that prevalence is elevated in comparison to people without dementia (Seignourel, Kunik, Snow, Wilson & Stanley, 2008). Teri and Wagner (1992) reported that most studies gave a prevalence rate of between 20-63% for symptoms of depression in people with dementia, which varied according to the informant, and a range of 0-86% for depressive disorders, although many studies reported a much smaller range of around 20-30% (e.g. Cummings, Miller, Hill, & Neshkes, 1987; Merriam, Aronson, Gaston, Wey, & Katz, 1988; Reding, Haycox, & Blass, 1985; Teri & Wagner, 1991). Studies have also reported that people with Alzheimer's disease are more likely to show symptoms of depression than older people without dementia (Knesevich, Martin, Berg & Danziger, 1983; Lazarus, Newton, Cohler, Lesser, & Schweon, 1987; Rovner & Morriss, 1989). Quality of life in people with dementia has also been the subject of much interest for researchers, and has become increasingly common as an outcome measure when assessing the course of the illness or the effect of an intervention (Thorgrimsen et al., 2003). However, there has been some debate regarding how to define quality of life in people with dementia (Ettema et al., 2005), and also whether people with dementia are capable of evaluating their own quality of life (Thorgrimsen et al., 2003). Lawton (1983, 1991, 1997) described a conceptual framework of quality of life for older people that consisted of four domains that are generally considered to be salient for people with dementia (Logsdon, Gibbons, McCurry, & Teri, 2002): behavioural competence, the objective environment, psychological well-being and perceived quality of life. The QoL-AD measure was developed from this literature, and was deemed to be reliable and valid for people with MMSE scores greater than 10, i.e. for people in the mild and moderate stages of dementia (Logsdon et al., 2002; Thorgrimsen et al., 2003). Several studies have shown that symptoms of dementia might adversely affect quality of life in people with dementia (e.g. Il-Seon, Carter, Masterman, Fairbanks, & Cummings, 2005; Samus et al., 2005), and other studies have suggested that maintaining identity might be a crucial factor in determining quality of life (e.g. Droes et al., 2006).

Given the extensive theoretical literature on the benefits of maintaining a sense of self and identity in people with dementia, it is surprising that there is little in the way of empirical evidence supporting this work. Kitwood (1997) highlights the importance of supporting the self in dementia through person-centred care, explaining that one of the key needs of people with dementia is to 'have an identity'. Ronch (1996) describes how the quality of life of an individual can be increased by supporting their identity, whilst George (1998) discusses links between the self and physical and mental health, role performance, quality of relationships, and subjective well-being. Although there is very little existing empirical work specifically relating to the relationships between identity and mood and quality of life, other literature exists that indicates more indirectly that some of these aspects of identity might be related to mood and quality of life. Whilst reports relating to the relationship between identity and levels of anxiety are scarce, some work related to possible aspects of identity and depression or quality of life has been undertaken. Lower levels of depression have been found in people with dementia with improved family and social contacts (e.g. Cohen-Mansfield, 2005; Droes, Meiland, Schmitz, & van Tilburg, 2004) and leisure activities (e.g. Adam, De Linden, Juillerat, & Salmon, 2000; Arkin, 2003; Schreiner, Shiotani, & Yamamoto, 2005; Buettner & Fitzsimmons, 2002), which might reflect the strength of role-identities in people with dementia. The salience of family support for quality of life, which might also be reflected in a family role identity, has also previously been documented (Droes et al., 2006; Katsuno, 2005). There is also a proposed relationship between aspects of memory functioning and quality of life, whereby several studies have observed an improvement in quality of life alongside an improvement in memory functioning or cognitive functioning in general (Spector et al., 2003; Woods, Thorgrimsen, Spector, Royan, & Orrell, 2006). Whilst this literature does not refer specifically to autobiographical memory, it is possible that this relationship might extend to different aspects of memory functioning. Although not extensive, this existing work does suggest that aspects of identity might be related to depression and quality of life.

Thus the specific research questions for this study are:

1. Are aspects of identity, as defined by Neisser's 'self-concept', associated with anxiety, depression, and quality of life?

2. If so, is it possible to predict the variance in anxiety, depression and quality of life from these aspects of identity?

Method

Design

This was a cross-sectional questionnaire-based study, examining the relationships between aspects of identity, mood, and quality of life. Ethical approval was granted by the School of Psychology Ethics Committee and by the North-West Wales NHS Research Ethics Committee (Appendix A)

Participants

Participants with dementia were recruited through two local memory clinics and also through a patient research participation register (NEURODEM) in North Wales. Inclusion criteria were a medical diagnosis of Alzheimer's disease, vascular dementia, or mixed Alzheimer's and vascular dementia using ICD-10 criteria (WHO, 1992). Participants had to be aged 60 or over, in the early stages of dementia as defined by an MMSE score of 18 or over, and fluent in English. Participants also had to have a close relative or friend who was willing to complete several questionnaire measures which required informant ratings.

Measures

Measures of identity

1) Strength and direction of identity (Appendix B)

Tennessee Self-Concept Scale (2nd Ed) (TSCS-II; Fitts & Warren, 1996). Identity Subscale.

Self-concept was assessed using the 21-item identity subscale of the TSCS and the five domains within this scale that represented different aspects of identity: personal, family, social, moral and physical domains. Each item is rated on a five-point scale

for self-descriptiveness from 'always false' to 'always true'. The adult scale has been standardised with people from 13 - 90 years of age, making it suitable for use with the participants from this study, and raw scores can be converted to T-scores for comparison with normative data. The TSCS-II scale also has good internal consistency, test-retest reliability, and construct validity (Coopersmith, 1981; Fitts & Warren, 1996), and the scale has been used successfully with people with dementia (Addis & Tippet, 2004; Naylor & Clare, 2008).

2) Role-identities

Self-Identity in Dementia Questionnaire (Cohen-Mansfield et al., 2000)

This questionnaire explores four types of self-identity roles in people with dementia; occupational roles, family roles, leisure activities and attributes. There are separate versions for the person with dementia, a close family member, and a staff caregiver. Only some of the items from the version for the person with dementia were used in this study. The four items used ask about how important each of the four roles are currently, on a scale of 1 (not at all) to 5 (very important).

3) Autobiographical memory

Autobiographical Memory Interview (AMI; Kopelman et al., 1990)

The AMI is a structured interview which measures both personal semantic and personal incident memory across three lifetime periods: childhood (Section A), early adult life (Section B), and recent adult life (Section C). Personal semantic memory assesses a participant's recall of personal facts such as the names and dates of birth of his/her children, whereas personal incident memory assesses the recall of specific incidents and requires access to episodic memory. This measure provides a total semantic memory score and a total incident memory score, in addition to semantic and incident memory scores for each of the three lifetime periods. The AMI is suitable for use with older people (Kopelman et al., 1990), and has been successfully used with people with dementia in previous studies (Addis & Tippet, 2004; Naylor & Clare, 2008).

4) Self-knowledge of personality traits (Appendix C)

Self and informant ratings of personality traits to measure self- knowledge (40 trait words selected from norms by Anderson, 1968, and Kirby & Gardner, 1972).

Although this method of measuring self-knowledge of personality traits has been used previously with people at all stages of dementia (Klein et al., 2003; Rankin et al., 2005; Ruby et al., 2009; Ruby et al., 2007), the list of traits used here was selected specifically for this study. Traits have been selected from norms to ensure that the adjectives cover a range of social desirability, and all score highly on familiarity and meaningfulness. The participant is asked to rate a list of 40 personality traits for how well the adjective describes their own current personality on a scale of 1 (not at all) to 4 (totally). The relative is also asked to rate the list of adjectives for how well they describe the participant's current personality. For each item, the difference between the participant's own score and the informant's score was calculated, and then these were totalled to give an overall discrepancy score for all 40 traits. The lower the discrepancy score, the more accurate the participant's self-knowledge is said to be.

Measures of mood and quality of life

Hospital Anxiety and Depression Scale (HADS; Snaith & Zigmond, 1994)

This is a 14-item self report measure that consists of two scales, one for anxiety and one for depression. Each item consists of a statement that must be rated from 0-3, according to how often the statement applies to the respondent. For both scales, raw scores of between 8 and 10 identify mild cases, 11–15 moderate cases, and 16 or above, severe cases. This measure is reliable and valid across all age groups (Spinhoven et al., 1997) and has been successfully used to measure symptoms of anxiety and depression in people with dementia (Wands et al., 1990).

Quality of Life - AD (QoL-AD; Logsdon et al., 2002)

This is a 13-item self-report scale that assesses physical health, mental health, social and financial domains of functioning in people with Alzheimer's disease. Each item asks about a specific aspect of one of these domains and the respondent is asked to rate how he/she feels about this aspect of his/her own life on a four-point scale, from 'poor' to 'excellent'. Responses are summed across items to give an overall score for quality of life.

Procedure

Participants and informants completed the questionnaires at home, with help from the researcher, as part of a broader study that included further measures in addition to those described above. Measures were completed in the same order for each participant, with identity-related measures being completed first, to reduce the possibility that answering the other questionnaires might influence how participants rated their identity. Participants were usually able to complete all measures in two visits, but several participants took three visits, one took four visits, and one took five.

Data analysis

Correlational analyses were performed to identify associations between aspects of identity and mood and quality of life. Backward regressions were then conducted to determine whether mood and quality of life could be predicted from models containing aspects of identity. Backward regression with the removal probability of $p > .10$ was used in SPSS v 15, with the predictors selected according to the variables that were most highly correlated with each aspect of identity. The stopping criterion used was the model with the highest adjusted R_a^2 value. In line with recommendations that suggest there should be at least 10 participants per predictor variable (e.g. Stevens, 1986), no more than four predictor variables were entered into each regression (although there were 50 participants, a small amount of missing data meant that the number of complete data sets in each analysis was slightly less than 50).

Results

Characteristics of the sample are given in Table 1. The mean age of people with dementia was 77.8 years (SD= 7.4, range = 60-91) and the mean MMSE score for people with dementia was 23.7 (SD= 2.7, range = 18-29), indicating that participants were in the early stages of dementia. There were no significant differences on measures of identity, mood or quality of life between male and female participants, between married/co-habiting participants and those living alone, or between participants with different dementia diagnoses.

Table 1. Characteristics of participants

Variable	N	%
Gender (female)	26	52
Diagnosis		
Alzheimer's disease	38	76
Vascular dementia	9	18
Mixed dementia	3	6
Status		
Married	32	64
Divorced	3	6
Widowed	11	22
Single	1	2
Co-habiting	3	6
Children (yes)	44	88
Education Level		
Secondary	45	90
College/University	5	10

Research question 1: Are aspects of identity associated with anxiety, depression and quality of life?

Scores on the identity-related measures are given in Table 2. The mean raw score on the TSCS represented a t-score of 48 and fell within the 42nd percentile with respect to the normative data (Fitts & Warren, 1996), suggesting that the scores were possibly

slightly lower than might have been expected for people of the same age without dementia. The role-identity with the highest score was the family role, with the occupational role scoring the lowest. The self-knowledge total discrepancy score suggested that participants showed a relatively accurate appraisal of their traits, with an average discrepancy of about 0.5 points per trait. Mean scores on both the personal semantic total and the autobiographical incident total of the AMI fell into the ‘definitely abnormal’ range according to the provided norms (Kopelman et al., 1990), which is in line with participants having a diagnosis of dementia.

Table 2. Scores on measures of identity

	N	Mean	SD	Range	Min-Max
TSCS Identity scale total	49	90.84	6.54	78.0-104.0	21.0-105.0
Physical items subtotal	49	19.96	2.43	15.0-24.0	5.0-25.0
Personal items subtotal	49	20.67	2.29	14.0-25.0	4.0-25.0
Family items subtotal	49	18.35	2.02	12.0-20.0	4.0-20.0
Social items subtotal	49	13.29	1.53	10.0-15.0	3.0-15.0
Moral items subtotal	49	18.57	1.62	14.0-20.0	1.0-20.0
SID Occupational importance	50	2.82	1.45	1.0-5.0	1.0-5.0
SID Family importance	50	4.72	0.57	3.0-5.0	1.0-5.0
SID Leisure importance	50	3.74	1.21	1.0-5.0	1.0-5.0
SID Attributes importance	49	4.06	0.94	1.0-5.0	1.0-5.0
Self-knowledge	42	24.14	5.65	11.0-43.0	40.0-120.0
AMI Personal Semantic Total	49	43.12	12.54	13.0-62.5	0-63.0
AMI Auto. Incident Total	49	10.16	5.65	1.0-23.0	0-27.0

Table 3 shows scores on the measures of mood and quality of life. The mean scores for anxiety and depression fell below the cut-off for clinical ‘case-ness’, but 3 participants fell into the mild category for anxiety, with one in the severe category, and 2 participants fell into each of the mild and moderate categories for depression (Snaith & Zigmond, 1994). The mean score for quality of life was in close agreement with scores reported by Logsdon et al. (2002) for people within the MMSE range found in the current study.

Table 3. Scores on measures of mood and quality of life

	N	Mean	SD	Range	Min-Max
HADS Anxiety	50	2.66	3.03	0-17.0	0-21.0
HADS Depression	50	3.18	3.08	0-14.0	0-21.0
QoL-AD Quality of life	49	37.92	1.34	23.0-44.0	13.0-56.0

Bivariate correlations between the mood and quality of life variables and potential predictor variables are shown in Table 4. Numerous identity variables were associated with the mood and well-being variables, many with moderate-sized correlations that would have been significant at $p < .05$ or $p < .01$, but all of these lost statistical significance after the Bonferroni correction was applied.

Table 4. Bivariate correlations between the measures of identity and measures of mood and quality of life

	Anxiety	Depress	Quality of life
TSCS Identity scale total	-.154	-.220	.346
Physical items subtotal	-.290	-.236	.353
Personal items subtotal	-.213	-.284	.242
Family items subtotal	.223	-.082	.204
Social items subtotal	-.142	-.136	.129
Moral items subtotal	-.030	.097	.150
SID Occupational importance	.051	-.153	-.040
SID Family importance	.073	-.295	.282
SID Leisure importance	.014	-.355	.261
SID Attributes importance	.015	.002	-.093
Self-knowledge	.030	.009	-.266
AMI Personal Semantic Total	.051	-.097	.280
AMI Auto. Incident Total	.105	-.133	.297

A Bonferroni correction was made for multiple comparisons, with the result that the p-value required to indicate a significant correlation was $p < .0013$.

* significant at $p < .0013$

Research question 2: Is it possible to predict the variance in anxiety, depression and quality of life from aspects of identity?

Backward regression analyses were performed, with anxiety, depression and quality of life being entered as dependent variables, to see whether these variables could be predicted from aspects of identity. The predictors entered were based on the correlation size between the variables as given in Table 4, such that the identity variables with the highest correlations with anxiety, depression, and quality of life were entered as predictors. The stop criterion was the model with the greatest R_a^2 value. The results are shown in Table 5.

Anxiety was significantly predicted by a model containing the TSCS family items subtotal, TSCS physical items subtotal, and TSCS personal items subtotal ($F_{3,45}=3.35$, $p<.05$, $R_a^2=.128$) with just the TSCS family items subtotal being individually significant. Lower levels of anxiety were associated with greater scores on the TSCS physical and personal items subtotals, whereas higher levels of anxiety were predicted by greater scores on the TSCS family items subtotal. The TSCS identity subscale total was entered into the regression but did not remain in the model.

Depression was significantly predicted by a model containing TSCS physical and personal items subtotals, and SID family and leisure subscales ($F_{4,44}= 4.66$, $p<.01$, $R_a^2=.234$), with just the SID leisure subscale being individually significant. Lower levels of depression were associated with higher scores on all of the predictors.

Quality of life was significantly predicted by a model containing the TSCS physical items subtotal, SID family importance, and AMI autobiographical incident total scores ($F_{3,43}= 6.145$, $p<.01$, $R_a^2= .251$), with just the TSCS physical items subtotal being individually significant. A better quality of life was associated with higher scores on the TSCS physical items total, the SID family subscale, and the AMI autobiographical incident total. The TSCS identity subscale total was entered into the regression but did not remain in the model.

Regression Analyses

Table 5. Backward regression analyses, predicting mood and quality of life from aspects of identity

	Anxiety		Depression		Quality of life	
R_a^2 for model	.128		.234		.251	
	β	p	β	p	β	p
TSCS Identity Subscale total	*				*	
TSCS Physical items subtotal	-.286	.052	-.234	.092	.429	.002
TSCS Personal items subtotal	-.162	.262	-.183	.181		
TSCS Family items subtotal	.292	.039				
TSCS Social items subtotal						
TSCS Moral items subtotal						
SID Occupational importance						
SID Family importance			-.243	.064	.233	.106
SID Leisure importance			-.337	.014		
SID Attributes importance						
Self-knowledge						
AMI Personal Semantic Total						
AMI Auto. Incident Total					.266	.066

* indicates that the variable was entered into the regression but was not part of the final model

Discussion

The aim of this study was to explore the relationships between aspects of identity, mood, and quality of life in people with early-stage dementia. Although much of the theoretical literature has implied a positive relationship between identity and aspects of mood and well-being, this is the first study to address the precise nature of this relationship.

Whilst none of the correlations were statistically significant, mainly due to the adjusted p-value (.0013) which resulted from the Bonferroni correction, anxiety, depression, and quality of life were significantly predicted from models containing aspects of identity, to differing extents (accounting for 12.8%, 23.4%, and 25.1% of the variance, respectively). All of the relationships were in the expected direction, with one exception, whereby the TSCS family items subtotal predicted higher levels of anxiety. That is, with the above exception, higher scores on the identity-related variables (or a lower score that represented better performance, as with personality self-knowledge) were related to lower levels of anxiety and depression, and a better quality of life. This is in agreement with previous literature, which has suggested that a retained sense of identity in general should support mood and aspects of well-being (Droes et al., 2006; Fazio, 2008; George, 1998; Kitwood, 1997; Ronch, 1996) and quality of life (Cohen-Mansfield et al., 2000; Droes, 2006).

The only significant predictor for a lower level of anxiety was a lower score on the TSCS family items subtotal. However, the TSCS physical items subtotal was also borderline significant at $p = .052$. The TSCS family items subtotal was positively associated with anxiety. This is surprising, since one might expect that better relationships and support from family members might reduce anxiety in the person with dementia. However, this finding supports results from Orrell and Bebbington (1996), who also found a relationship between anxiety and aspects of social support and relationships with relatives in people with dementia. Their study found associations between anxiety and high social contact, and anxiety and dominance in close relationships. The authors attributed this to a possible relationship between high social contact and increased dependency, and possible negative communication styles. A further possibility is that since caring for a relative with dementia is known to increase symptoms of anxiety and depression in caregivers (e.g. Mahoney, Katona, & Livingston, 2005; Schulz, O'Brien, Bookwala & Fleissner, 1995), it could be that the person with dementia is aware of this change in his/her relative, which in turn is

influencing his/her own level of anxiety about the carer. Higher scores on the TSCS physical items subtotal might reflect an absence of pain that might accompany poor physical health, or the ability to participate in desired activities that might reduce anxiety, such as physical exercise (De Moor, Beem, Stubbe, Boomsma, & De Geus, 2006; Salmon, 2001), or other activities with friends and family, which might also reduce anxiety.

The only individually significant predictor for a lower level of depression was a higher score on the SID leisure subscale, although the SID family subscale almost reached significance at $p = .064$. The relationship between these aspects of identity and depression supports theoretical literature, specifically the positive effects of improved family support, social contacts, and leisure activities on identity. Lower levels of depression in people with dementia have previously been associated with family and social contacts (e.g. Cohen-Mansfield, 2005; Dries et al., 2004) and leisure activities (e.g. Adam et al., 2000; Arkin, 2003; Buettner & Fitzsimmons, 2002; Schreiner et al., 2005), which supports the associations found between these variables in the current study.

The final dependent variable was quality of life, for which only the TSCS physical items subtotal was significant. The advantages of physical health for lower levels of anxiety have already been discussed, and the relationship between physical health and quality of life may well occur for the same reasons (e.g. Acree et al., 2006). The AMI autobiographical incident total almost reached significance as a predictor at $p = .066$. The potential relationship between various aspects of memory functioning and quality of life has previously been recognised. Although there are few studies that have directly examined the association between autobiographical memory functioning and quality of life, several studies have reported an increase in quality of life alongside improved memory functioning following some sort of intervention such as cognitive stimulation (e.g. Spector et al., 2003; Woods et al., 2006), or studied the relationship between quality of life and cognitive functioning more generally (e.g. Sloane et al., 2005). One could speculate that an intact autobiographical memory might enable the person with dementia to reflect on his/her memories and share these with other people, thus leading to more satisfying social engagements involving reminiscing about past events. Alternatively, better memory functioning could be associated with less performance-related distress, which in turn might predict a better quality of life. Without further research the precise reason for this relationship remains unclear. With respect to self-knowledge of personality, it might be valuable

to see oneself in the same way as a spouse or another close informant does, since discrepancies in this area could potentially cause disagreements affecting the quality of close relationships.

Thus overall, a retained sense of identity in people with early-stage dementia can contribute towards improved mood and quality of life, although there must also be a number of other contributing factors that are not identity-related. In general, the results agree with the previous literature, and also support the notion that it might therefore be valuable to support identity in people with dementia where relevant, with the aim of also maintaining or improving mood and quality of life. Whilst a number of studies have already attempted to support identity through interventions aimed at people with dementia, these have had limited success and results are mixed (see Chapter 4). These existing interventions have mainly identified memory as a target for improvement and relied heavily on reminiscence techniques, but the current study suggests that other factors might also be important for supporting mood and quality of life. This might include supporting physical and leisure activities where possible, as well as maintaining positive relationships with families and other social contacts, as suggested by the predictors of mood and quality of life in this study. Such factors have already been associated with improvements in aspects of mood and well-being (e.g. Logsdon & Teri, 1997; Teri et al., 2003).

Limitations of this study include the fact that participants who volunteered to participate may represent a select group of individuals, who could be more confident or socially active than those who declined to take part. Obviously, the results cannot be generalised to people in the more severe stages of dementia, and further work in this area would be of value. This study was also quite limited with respect to the dependent variables - it might also be valuable to consider how aspects of identity are related to other salient aspects of well-being, such as self-esteem and quality of relationships with friends and relatives.

In summary, this study is the first of its kind to explore whether aspects of identity serve as predictors of mood and quality of life in people with early-stage dementia. The results mostly concur with the theoretical literature, and also provide support for the development and implementation of interventions designed to support identity in people with dementia who are experiencing problems in this domain, which to date have been based on little empirical work. Although further work is required to understand more precisely how aspects of identity are related to mood,

quality of life, and other potential variables, this study has provided a useful starting point from which future work may be developed.

Chapter 8: I'm still the same person: The impact of early-stage dementia on identity

Summary

Research suggests that the onset and progression of dementia may pose a threat to a person's sense of identity. This qualitative study used Interpretative Phenomenological Analysis to explore participants' perceptions of the impact of dementia on their identity. Participants were ten people with dementia. The four themes emerging from the data represented participants' views on aspects of their current identities, whether they believed that dementia would alter their identities in the future, perceptions of how dementia had affected their lifestyle, and relationships with friends and family. The analysis suggested that for the most part, participants felt that little had changed with respect to their identities as a whole, but most identified features of themselves that were different than they had been prior to the onset of dementia. Thus it appeared that participants were in a state of flux, experiencing both continuity and change in their sense of identity simultaneously.

Caddell, L.S., & Clare, L. (2011). I'm still the same person: The impact of early stage dementia on identity. *Dementia, 10*, 379-398.

Introduction

Recently, there has been much debate in the literature regarding the extent to which identity remains intact in people with dementia. Despite early reports that people with dementia lose their sense of who they are (e.g. Cohen & Eisdorfer, 1986; Fontana & Smith, 1989; Herskovits, 1995) more recent studies suggest that although identity may be compromised in some way, it is not necessarily lost (see Chapter 2). This paper presents results from a qualitative study using Interpretative Phenomenological Analysis (IPA) which focused on the views of people with early-stage dementia with respect to how they perceive the impact of dementia on their sense of identity.

Many studies have concentrated on the experiences of people with dementia, and on involving them in research that allows their experiences to be shared in their own words (e.g. Clare, 2003; Langdon, Eagle, & Warner, 2007; Snyder, 2009). Studies specifically concerning the self in dementia have used both qualitative and quantitative methodologies, and have been based on a variety of concepts and models (see Chapter 3). A number of qualitative studies have considered aspects of the experience of developing dementia, and in so doing have commented on self and identity. Some of these studies have suggested that people with early-stage dementia are able to implement strategies in order to preserve their identity (e.g. Beard, 2004; Gillies & Johnston, 2004). Clare (2003) and Pearce, Clare and Pistrang (2002) discussed coping strategies used by people with early stage Alzheimer's disease, which ranged from self-maintaining responses aimed at maintaining a prior sense of self, to self-adjusting responses aimed at integrating changes into the self-concept. Accounts of how participants protect their sense of self or integrate changes are described in the context of the range of coping strategies employed, with a particular focus on participants' awareness of their illness. However, these studies examine methods that participants might use to protect their sense of self, as opposed to focusing directly on how people with dementia actually experience their sense of self. One recent study (MacRae, 2010) utilized a symbolic interactionist perspective to focus more directly on asking participants about their sense of identity, and whether they had experienced any changes or were worried about potential changes in their identity. This theory-guided study suggested that the participants had maintained various meaningful components of identity using a range of strategies, and had not noted any major changes since the onset of dementia. However, to date there are no

exploratory thematic analyses on this topic that present the perspective of the person with dementia.

The purpose of the current study was to focus more specifically on whether people with dementia felt that they had changed as a person, what kind of person they thought they were, and how they thought their identity might be affected by dementia in the future. Previous studies regarding the self in people with dementia have focused on issues such as roles, relationships, personality, and autobiographical memory (see Chapter 2). Neisser's (1988) five-factor model of the self includes a broad range of possible components of identity, including those outlined above, and Chapter 3 discussed the use of this framework for studying the self in people with dementia. However, a thematic analysis would allow participants to express what they believe to be aspects of their identity without confining the possible responses to constructs which are defined prior to the study. Given that the emphasis of this study was on what participants think and believe about the topic, i.e. their subjective experiences and the meanings that they have attributed to these experiences, interpretative phenomenological analysis (Smith, Osborn, & Jarman, 1999) was considered to be an appropriate approach to use in analysing the data. Interpretative Phenomenological Analysis can be used to explore the participant's view of the topic in question, but also acknowledges that the researcher's own beliefs and understandings play a part in the interpretation of participants' accounts.

Method

Participants

Participants had an ICD-10 diagnosis of Alzheimer's disease or vascular dementia and were classified as being in the mild stage of severity (a score of 18 or more out of 30 on the Mini Mental State Examination; Folstein et al., 1975). Participants were identified from Memory Clinic records and were required to speak English fluently and to be capable of giving informed consent.

Five women and five men aged between 65 and 88 (mean age 81.1 years, SD = 6.89 years) who were participating in a wider study on identity in dementia also gave consent to be interviewed in addition to completing measures for the wider study. This subsample represents a typical profile of people visiting a memory clinic

in this area. For the wider study, participants were first contacted by the memory clinic or another person from the clinical team, and those who were interested in participating contacted the researcher. The people who were invited to participate in the extra session tended to be those with whom a good rapport had been established and who were willing to undergo an extra session with the researcher. No participants who were taking part in the wider study and who were then invited to participate in the interview refused, although a number of people refused the invitation to take part in the wider study. All participants were of white European origin, had been born in the UK or been resident in the UK since childhood, and had been educated to secondary school level. The male participants were all retired, and their occupations had included being a foreman, member of the emergency services, engineer, factory worker and hotel owner. The female participants were all retired and their occupations had included typist (two participants), cook, nurse, and a factory worker who also worked in retail. All participants lived at home; eight lived with their spouses and two lived alone. The area from which participants were recruited was mainly rural or semi-rural. Participants' Mini Mental State Examination scores ranged from 22 to 28 (mean 24.9, SD = 1.91). Throughout this paper participants' names have been replaced with pseudonyms to protect their anonymity.

Ethical approval was gained from the School of Psychology Ethics Committee and the North West Wales NHS Research Ethics Committee prior to the commencement of the study (Appendix A), and permission was also gained from the relevant NHS research governance committees for access to participants.

Procedure

Informed consent was taken prior to the beginning of the session, and included consent for the audio-recording of the interview. An individual interview was conducted with each participant, lasting between 30 and 90 minutes, and was recorded for transcription. The interviews were conducted using open-ended questions which enabled participants to talk about their experiences freely. An interview schedule was developed which outlined the main topics to be explored, and further prompts and questions were used where appropriate. The main areas of exploration for the interview were:

- How the participant described him/herself and what he/she thought of as his/her important characteristics.
- What sort of difficulties the participant was experiencing as a result of memory loss and other symptoms of dementia and how he/she was coping with these issues.
- Whether the participant had noticed any changes in him/herself and whether he/she thought that other people had noticed the changes.
- Whether the participant felt that he/she was likely to experience changes in identity in the future.

Data analysis

The interview data were analysed using Interpretative Phenomenological Analysis (Smith et al., 1999). The aim of this analysis was to extract common themes across the interviews, in a rigorous and thorough manner. Verbatim quotes were used to illustrate each theme, and participants' own words were used to label the themes. Interviews were first analysed individually, and margin notes were grouped into themes which were then grouped into super-ordinate themes, i.e. groups of themes which appeared to be related (Appendix E). Once each interview had been analysed in this way, the group-level analysis commenced. All themes and sub-themes from the individual analyses were drawn together and grouped with similar themes from other interviews so that new clusters of themes were formed, each of which could contain several sub-themes (Appendix F & G). Themes used in the final account represented the views of the majority of the participants; thus only themes represented in at least two-thirds of the transcripts were included. To ensure credibility, it is important to address possible sources of bias. In this study, the second author followed the analytic process from the initial individual analyses through to the final analysis across all interviews, and where any questions arose regarding the appropriate categorisation of an extract to a theme, or a sub-theme to a super-ordinate theme, this was discussed until a consensus was reached. The first author returned to visit three of the original participants to see whether they felt that their experiences had been well represented in the account. These particular three participants were chosen because they were willing and able to participate in another session with the researcher, and also because they remembered having participated in the original interview and so were able to

reflect on the account produced by the researchers with respect to what they had expressed in the initial interview. All three participants believed that their experiences had been understood and interpreted accurately. Finally, a nurse and an occupational therapist from a local memory clinic who are in daily contact with patients with dementia were asked to examine the results section. Both agreed that it reflected the experiences of people with dementia that they had worked with, and one commented that, when working in dementia care, she often heard the very same words and sentences as the verbatim quotes from participants recorded in the results section.

Results

Four main themes emerged from the data, which are illustrated in Figure 1, and described below. The four themes each represent the experience of the person with dementia as a tension between maintaining a prior sense of self and noting changes to the self. For each theme, the two perspectives of continuity and change are described, followed by a section demonstrating how the tension between the two perspectives was exhibited. Within each theme, most individuals acknowledged both continuity and change, as illustrated in Table 1.

Theme 1. 'I'm still the same person' versus 'I'm different to what I used to be'

'I'm still the same person'

When asked what were the most important things about them, nine participants described themselves in terms of personality traits and in the context of relationships with others. Most participants held a particular concept of themselves, with two participants describing themselves and then stating:

That's the sort of person I am. (Mary)

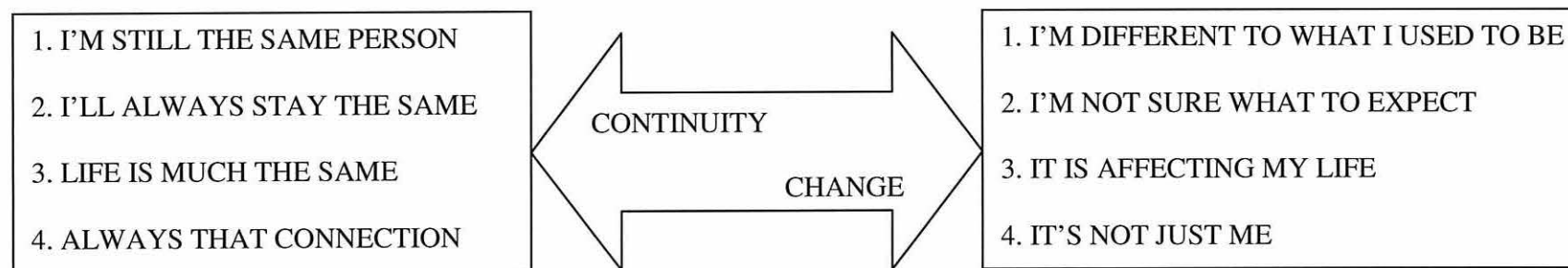
Other participants talked about having a 'good sense of humour', and being 'friendly' and 'outgoing':

I consider myself a reasonable person you know, I get on with most people...
(Gordon)

Table 1. Table to show prevalence of each theme within participants' accounts

Theme	R	D	J	F	G	H	M	T	A	B
1. I'm still the same person	X	X	X	X	X	X	X	X	X	X
1. I'm different to what I used to be	X	X	X	X	X	X	X	X	X	X
2. I'll always stay the same	X	X	-	X	X	X	-	X	X	X
2. I'm not sure what to expect	X	X	X	-	X	X	-	X	X	X
3. Life is much the same	X	X	X	X	X	X	X	X	X	X
3. It is affecting my life	X	X	X	X	X	X	X	X	X	X
4. Always that connection	X	X	X	X	X	X	X	X	X	X
4. It's not just me	-	X	X	X	-	X	X	X	X	X

Figure 1. Diagram illustrating the four themes organised according to representation of continuity or change



Six participants also mentioned traits that they did not possess, such as being a 'dictator' and being 'lazy' or 'aggressive':

I think I'm not one of the types who are aggressive...well I'm too small to be aggressive! (Gordon)

Thus most participants appeared to retain information about themselves which was often justified with examples, and could describe what they saw as important aspects of their selves. When asked about any changes in their sense of self over time, all participants felt that they had remained mostly unchanged since the onset of dementia. Participants described feeling the same overall, and also talked about particular aspects of themselves that they felt had not changed:

I'm still the same silly bugger (Harry)

When suggesting more specific aspects of themselves that hadn't changed, participants talked about traits such as 'honesty' and 'being respectful':

I've always stood up for myself, but I've never been rude to people and that intentionally. Erm, and it's still the same today. (Robert)

Three participants talked about their attitudes and religious and political beliefs surviving the onset of dementia:

No problem, we still go to church on a regular basis, and er, I –no, it hasn't affected anything like that. (Robert)

One gentleman described how his priorities and aims in life had remained the same over time and had not been affected by the onset of dementia:

Well, er, the same as it's always been...to enjoy life, be nice to people and love my wife, and daughter, and –and do things about the house...all that's not changed at all. It's just that I've got a bad memory! (Robert)

This provides an interesting insight into what people consider to be important aspects of their selfhood. Participants volunteered information about their personality traits, relationships with friends and family, leisure activities, attitudes, beliefs and opinions, suggesting that identity was viewed as multi-faceted. These quotes demonstrate that participants were able to identify numerous aspects of themselves that had remained constant over a long period of time, and few explicitly made an association between dementia and changes to the self.

'I'm different to what I used to be'

All participants were able to describe ways in which they were different to how they had been before the onset of dementia, but they mostly talked about quite specific changes such as symptoms and emotional reactions to the illness rather than changes to their sense of self as a whole. Only one participant (the participant with the lowest MMSE score) felt that she was a very different person to what she had been before the onset of Alzheimer's:

No, I'm not (the same person), because my lifestyle is so different.... I like being out and amongst people, erm, but I would say that this illness, if that's the right word to apply to it, has meant that my lifestyle has gone from that, to that...inevitably I think. (Mary)

Mary went on to describe how her circumstances (specifically living in a rural area where Welsh is widely spoken and the first language for many people) had resulted in this change in her lifestyle, which appeared to exacerbate the difficulties caused by the onset and progression of dementia:

I can't drive, I'm not allowed to drive, and living here, that can be very limiting if you can't drive...living here has resulted in me living in much greater social isolation than if we'd stayed in (city). Erm, and I think that I probably would have been a very different person then...and of course living where we live, where the first language isn't English, has made a difference as well...

This highlights how much of an influence external circumstances can also have on a person with dementia. It is possible that the effect that the dementia has had on Mary might not have been so severe if she had felt more connected and involved with her social network.

Nine people described changes in mental functioning that they had noticed since the onset of the illness, such as memory impairments and difficulties in word finding. For one participant in particular, this led to him being positioned differently in a religious group he had belonged to for many years:

If you can't talk back, you have to be talked to really...and that's where the position lies really... 'cause I can't talk back to people can I? Really, in a way...sometimes you can, there's no hard and fast rule....but it's definitely different to what I used to be...something, something in the brain really, it is, isn't it? (Ted)

Thus one can see that the symptoms of dementia can impact upon aspects of identity indirectly, by making communication difficult and thus weakening social ties with friends and family. All participants also described the feelings they experienced as a result of their symptoms. Two participants felt 'embarrassed' about their forgetfulness, and another worried that he would upset people through not remembering their names:

To me it feels like I'm insulting them by not remembering their name...I don't like that at all. (Harry)

Six of the participants described the anger that they experienced as a result of the frustration of forgetting:

When it happens and I have a problem I call myself the biggest bloody fool that ever lived. (Harry)

Anger and frustration was a common reaction to difficulties amongst the majority of the participants. Six participants described changes in their emotional experiences as a

result of their difficulties, for example worrying about their symptoms or feeling upset or 'down' about their current situation:

What worries me is the fact...have I said something, and I've forgotten I've said it, and what worries me...am I saying the same thing, you know, which I think I have been said before...that's what worries me (Agnes)

Three participants also reported feeling more lonely since the onset of dementia, which had imposed limitations on their ability to visit or interact with relatives or friends:

Well I suppose I don't go out so much....see I used to go out quite regularly. I seem to have stopped it all now. I'm quite happy as I am, but...I suppose it would be different to have friends. (Dorothy)

Thus overall it appears that all participants were able to think of ways in which they differed to their pre-dementia selves, but these tended to be very specific things related to symptoms and emotional reactions to the symptoms, rather than feeling as though they had changed on the whole as a person. Few people highlighted any major changes in personality and nobody mentioned changes in attitudes, opinions, beliefs or preferences since the onset of dementia.

Tensions between 'I'm still the same person' and 'I'm different to what I used to be'

Interestingly, all participants were able to describe both ways in which they had remained the same and ways in which they had changed. For example, Agnes stated that:

I'm the same old thing' (Agnes)

Later, Agnes went on to describe what she saw as a major change in herself, referring to a long-term hobby of hers:

I couldn't – I can't – I don't cook, no. I have changed a lot in the way that I don't cook (Agnes)

However, she continued to watch cookery programs on television, and had kept her favourite cookery books, which suggested that her interest in cookery had been maintained although she did not feel able to cook herself.

Another example concerns Joan who also described herself as being 'ordinary' and having changed very little, if at all:

I'm just an ordinary mum, you know, and grandmother...I think I haven't changed (Joan)

Later, Joan went on to describe incidents which had made it clear to her that something had indeed changed, although she was unsure at first what was happening to her:

I knew something wasn't quite right. (Joan)

I said to (my husband), 'that's it now, I'm losing it now' (Joan)

As with all participants, although Joan had stated that she believed that she had not changed as a person, she was also able to describe the feeling that something had changed, although initially she was not quite sure what it was. Thus it appears that participants are experiencing a tension between seeing their identities as remaining intact, yet noticing aspects of themselves that have changed.

Theme 2: 'I'll always stay the same' versus 'I'm not sure what to expect'

'I'll always stay the same'

Eight participants stated that they did not think, or were hoping that they would not, change as a person in the future:

No, I don't think so, I don't think I'll ever change. (Gordon)

Three also pointed out that they had been the same for a very long time, and were not expecting to have much time left in which to change, some commenting that they were 'stuck in a rut' or making the point that they had not changed 'so far', and thus thought it unlikely that they would do in the future:

I'm too old to change now! I'm set in my ways! (Betty)

Others focused on specific things about themselves that they did not believe would change, such as aspects of their personality, pride in one's country, or maintaining courtesy to others:

I like to think that er, my generation have certain levels in which to maintain...courtesy to the opposite sex for instance, erm, pride in your country... that will never change. (Robert)

Half the participants expressed a desire not to change, and were hoping that their attitudes and opinions would stay the same. Interestingly some participants also referred to their memory when thinking about the possibility of change in the future, with one lady specifically making a link between her memory and how she is as a person:

I wouldn't like to think that my memory went and I couldn't –you know, my mind went and I could be different. I wouldn't like that. (Betty)

This suggests that at least some participants had considered the possibility of changes in themselves in relation to having dementia, and how the progression of the memory impairment could potentially change them as a person.

'I'm not sure what to expect'

Whilst the majority of participants believed that they would remain the same person as the dementia progressed, seven participants also expressed uncertainty about what

to expect in the future. Even those who had indicated elsewhere in the interview that they were sure they would not change as a person appeared to have some doubts about how they might be affected as the illness progressed:

I wouldn't like to say! I haven't started throwing things at people yet....(Dorothy)

Others expected some change in themselves over time but were not specific about what they thought might change:

What will be in front is another thing. Things will change in time won't they...with the dementia you know....(Joan)

Four participants talked about the possibility of deterioration and their desire to maintain their functioning. They also described fears about losing abilities that contributed to their sense of who they are, the loss of which could potentially pose a threat to how they define themselves:

I don't want my mind to deteriorate...because at the day care centre I see people who are really bad, and they're quite, you know, one or two are quite childish, and I would hate to get like that. Erm, I want to be able to keep my mind the way it is. I mean it doesn't –the memory's not as good as it was, but I wouldn't like to think I would get –go too far down. (Betty)

Despite this, some participants were doing their best to 'look on the bright side' and maintain 'positive thinking', whilst others were hoping for a cure in the near future:

I'm hoping they'll find something that will stop it deteriorating...I dread the thought of it getting worse....you know, if I couldn't communicate....
(Robert).

Thus overall it is apparent that some participants were wrestling with uncertainties about their future, and the potential for dementia to affect their functioning. Several participants linked this potential deterioration in functioning to a consequence that

might threaten their sense of self or identity, by making them 'childish' for example, or by robbing them of their speech or ability to recognise their spouse:

The memory...I daresay that's what creeps on...don't you go completely speechless? (Agnes)

If it gets any worse and I can't recognise my wife or something like that, you know...(Ted)

However, in the majority of participants there appeared to be little concern that they would simply become 'a different person' or change beyond recognition as a result of the dementia; the focus was on specific aspects of functioning and the possible worsening of symptoms.

Tensions between 'I'll always stay the same' and 'I'm not sure what to expect'

Over half of the participants expressed conflicting ideas about the potential for change in themselves in the future. Whilst some participants expressed a desire and determination not to change in the future, some of these same participants also acknowledged that they were not sure whether their memory loss or dementia would change them. Ted expressed his confidence at one stage during the interview that he would not change as a person as the dementia progressed:

If I haven't changed since (childhood), I'm not likely to change again now am I? (Ted)

Yet during another part of the interview he admitted that he was unsure how the dementia might change him:

I don't know...you can't give an answer to that, can you? (Ted)

Another participant was also confronted with the same tension between continuity and change with respect to the future. Harry was very family oriented, enjoyed an active social life, and valued the traditions and positive memories of his lifetime that he still

retained. This was a big part of how he defined himself, and he described several times how he did not expect these important things about him to change in the future:

I'm still the same, always will be. I definitely think that the guys I knew when I was 21 would probably recognise me now... (Harry)

Yet he also expressed some uncertainty about his future and his thoughts on how the dementia would affect him:

I'm not sure what to expect...we'll just have to wait and see (Harry)

These examples reflect a common theme among participants. Most were hoping and expecting to remain the same in the future, but some harboured doubts about how things would progress and how they would be affected as a person, and again this was the source of some tension between the expectations of continuity and change.

Theme 3: 'Life is much the same' versus 'It is affecting my life'

'Life is much the same'

All participants described how little life had changed since they had been informed of their diagnosis of dementia or become aware of memory difficulties. Participants talked about how their daily lives had remained much the same, and how the dementia had had little impact overall on their daily functioning:

I still carry on as nothing's happened as such, 'cause nothing major has happened. I just carry on...I do everything, I run the house, pick the money off the bank...I'm taking it all in my stride at the moment. (Joan)

Most participants described how they were still able to carry out their daily activities and leisure pursuits, and the majority emphasized that they were just carrying on as they had before the dementia became evident:

I gallantly go around doing everything I used to do (Dorothy)

Most participants also talked about how they had managed to limit how much time they spent worrying about their diagnosis, and appeared to be taking it one day at a time:

I don't walk around down in the dumps or anything (Dorothy)

I'm not particularly worried about anything (Frank)

Thus it was evident that for all participants there was a lot about their lives that had remained constant since the onset of dementia. Participants described how they were continuing to participate in the things that they enjoyed doing, and all of the usual routines of daily living, perhaps with minor adaptations in some cases.

'It is affecting my life'

Even though all participants emphasized the continuity in their lives, it became apparent that nine were able to identify some ways in which they had had to adapt to their evolving circumstances. For some, these changes were described as relatively minor:

The only thing that does affect me is that sometimes when I go shopping for more than one item, I tend to forget some of them. (Harry)

Others experienced more significant changes. Seven participants found that they were unable to undertake their leisure activities to the same extent as they used to, or had become less involved in activities in general:

Now I tend to do things because they need doing, or M (wife) has asked me to do something, whereas before I was doing things because I enjoyed them.
(Harry)

Well, as my memory's got worse and worse, erm...I've –I've become less and less involved in things going on. (Mary)

Others had completely given up previous activities, with some people explaining that they had lost confidence or were worried about ‘making a fool’ of themselves if they tried to continue at their previous level of functioning:

I’m thinking if I was up and dancing now I’d make a fool of myself (Gordon)

Thus participants were all able to describe some changes they had noticed since the onset of dementia. Some of these changes were manageable by implementing certain strategies to overcome them, for example making a shopping list, but others were less easily dealt with. Many participants felt as though they would not be able to undertake activities that they had previously enjoyed, and some stopped making an effort to maintain such activities out of a fear of embarrassing themselves.

Tensions between ‘Life is much the same’ and ‘It is affecting my life’

Overall, despite all participants explaining how their life had generally not changed much, all participants could also describe some things that had changed for them. Some participants made comments within the interview that appeared to directly contradict earlier statements. Robert made repeated comments to emphasize how the dementia was not affecting his everyday life at the moment:

It doesn’t appear to affect my everyday life...I do everything else as I did it before (Robert)

However, a little later on in the interview he stated:

It is affecting my life obviously. I’ve always had a very good memory and this is a shock to me. I say to many of my friends, when I’ve met up, ‘hello’, I’ve said, ‘sorry, I’ve forgotten your name’. (Robert)

Similarly, other participants described how the dementia or memory difficulties had only had a minimal effect on their life, only to follow this with statements about

various aspects of their lives that had changed significantly. Mary commented on how little had changed in her lifestyle overall:

Well there's not been any sudden dramatic change in life (Mary)

Mary went on to later describe how her lifestyle had changed significantly after the onset of dementia, in a way that affected many aspects of her everyday life. She felt that the constraints that were imposed on her by situational factors such as where she lived and the language that she spoke had created limitations in terms of her lifestyle, particularly in terms of relationships with family and friends :

The fact about my life is that it's very very shallow now...I wasn't a shy person or a reclusive person at all, erm, but now...my lifestyle is so limited and narrow. (Mary)

The interviews demonstrate that all participants experienced feelings of continuity, in the sense that their lives had remained the same, whilst also registering differences that did not match this experience.

Theme 4: 'Always that connection' versus 'It's not just me'

'Always that connection'

Family and friends clearly played a big part in most of the participants' lives. The majority of participants lived with their spouse, whilst others were dependent on other relatives and friends for support and company. Participants were grateful that for the most part, these relationships had not been affected, and were also pleased to find that most people treated them the same in spite of their difficulties:

I converse with all of them and they converse with me, and I don't –I don't feel as though I'm being treated differently because I've got a memory problem. I feel as though they're treating me as if I haven't got a memory problem, because I can still converse with them, you see, and er dance with them...no, there's no problem there. (Robert)

Participants described how much they valued contact with other people, whether these were friends, family, or just people that they met on a walk or in the local shop, and it was clear that this sort of contact was important to many participants:

If –if I go to the shop to buy anything, they all chatter away, you know, so you can always have a little talk to somebody. (Dorothy)

Family was very important to all participants, and all valued contact with relatives, whether it was their spouse who lived with them, a visit from another relative or just a conversation on the telephone:

I've got a good wife you see, she's brilliant, she always helps me...and a wonderful daughter, lots of good friends, you know –what more could I wish for really? (Robert)

Friends were equally important to at least six of the participants, and there was a sense that the onset of dementia had made little difference to the contact that the participants had with their friends. Certainly, time with friends was highly valued:

I still...have put a great store on real friendship...real friendship. There's not a lot of it about so when you get one or two real friends, that's important. (Harry)

It seems as though relationships with family and friends were very important for all participants, and for the most part it appeared that these relationships had been maintained. This was proving valuable for participants who expressed gratitude for the support they were receiving.

'It's not just me'

Despite the expressed importance of social contact and relationships, four participants in particular did have worries about close family members or friends, and were aware

of the struggle that such others were also undergoing to adapt to the situation. Some were concerned about the impact of dementia on their spouse:

She wants to go somewhere, out and about with someone, and she wants to take her husband with her you see. I feel sorry for her really because I would rather not go. (Ted)

However, most of these participants described how they managed to 'get by' through the implementation of strategies to manage any problems:

You've got to live together so you might as well work it out hadn't you?
(Dorothy)

Other participants seem to have been faced with a 'wall of silence'. They were unaware whether others knew about their diagnosis or difficulties because they had deliberately not told people, and people they were in contact with had not made any remarks about it:

They don't say anything and I don't say anything. Nobody has passed remarks at all...I've never met anything or anybody who's been nasty or sarcastic about it. (Dorothy)

Despite the silence on this issue, some participants believed that others must have noticed, but perhaps had been 'too polite' to say anything:

Oh they must have (noticed), mustn't they....they must have done. (Ted)

It is apparent that participants did notice some changes in their relationships with friends and family. However, many found that for the most part, their relatives 'put up' with any difficulties and they did not perceive any major impact on their relationship at this stage.

Tensions between 'Always that connection' and 'It's not just me'

Eight participants reported that their relationships with others had persisted, but also acknowledged some changes. Harry talked about how important his relatives had remained to him over time and how this had not changed since the onset of dementia:

We've never just faded away like some families do, we've always had that connection. (Harry)

Yet despite this ongoing 'connection' and the close relationship with his wife, Harry went on to describe the effort he had to make to ensure that this relationship maintained its stability:

....sometimes I have to be quite careful because it would be quite easy to get angry with (wife), which wouldn't be fair. Sometimes I'm not successful at doing that, sometimes I do it reasonably well, but er, I try not to...'cause I know it's wrong, it's not her fault I can't remember. (Harry)

This illustrates the tension that had entered into an otherwise harmonic relationship as a direct result of the symptoms of dementia. Another gentleman, describing his ongoing relationship with his wife, emphasized his love for her, which had not changed since the onset of dementia:

You've come together haven't you, to understand each other, that's what we mean by love. (Ted)

However, Ted also acknowledged the difficulties that his memory impairments caused in the relationship with his wife, and worried about how these difficulties might affect her:

And not too good for her really, if I'm thinking of saying –telling her something that I've heard somewhere, and I go to tell her, and I've forgotten...I've forgotten to tell her. (Ted)

These examples suggest that whilst relationships are being maintained and valued, the symptoms of dementia were a source of concern for participants, who worried about the effect these had on their partners. Generally, there was recognition that such difficulties could impact upon their partners, who in turn might find it difficult to cope, which had the potential to cause changes in their relationship.

Discussion

The aim of this qualitative study was to investigate how people with dementia perceive the effects of dementia on their sense of identity. Although other studies have described a tension between the maintenance of the self and the incorporation of changes, this has mainly been described with particular reference to coping strategies (e.g. Clare, 2003; Pearce et al., 2003), rather than a specific focus on changes to self and identity.

Similar to previous research, the four themes that emerged from this analysis highlighted the tension between continuity and change in participants' lives. Whilst the emphasis appeared to be on continuity, all participants were able to describe changes that had occurred. For the most part, participants felt that nothing 'major' had changed about themselves as a whole – the things that had changed seemed more specific than changes to their self in general. The majority of participants talked about both continuity and change with respect to each theme, and all participants exhibited this pattern for at least three of the four themes. Participants reported continuity particularly in terms of their personality, their political or religious beliefs, their outlook and priorities on life, and in the things that they enjoy. Changes tended to be more related to the symptoms and effects (practical and emotional) of the dementia and its progression. It is particularly interesting that people described changes in themselves in terms of things that they could or could not do any more, suggesting that identity is not only something that is 'within' us, but also is demonstrated through our actions and activities. Obviously, if identity is dependent upon such activities, this has implications for people with dementia as the disease progresses and abilities are compromised.

An intriguing feature of the interviews was the uncertainty of most participants relating to the future effect of dementia on their identity. No participants explicitly declared that they expected their identity to change in the future, but many

registered uncertainties surrounding this issue, and did not rule out the possibility of such change. There could be a number of possibilities underlying this uncertainty. Some participants had seen relatives, friends, or other individuals with dementia and witnessed changes in identity in these people, so were aware that dementia might affect their identity, whereas other participants did not have such experiences. Whilst some participants appeared to genuinely believe that they would not change in the future, others acknowledged that they did not like to think about the future and preferred not to confront impending difficulties until it became necessary. For some, the potential for such change might simply be too threatening or too painful to acknowledge, and was therefore not confronted at the time of the interview. It could be that the threat of potential changes to self in the future might be enough to also threaten the stability of the current self in some way, and thus refusing to acknowledge potential changes in the future might actually be an act of self-preservation for the present. Given that a number of participants made comments regarding the 'limited' time that they had left, this strategy might enable them to enjoy this time to maximum benefit.

This study highlights the complexity of how participants experience their sense of self and identity. It is clear from the interviews that most people were able to describe both continuity and change in the context of each theme during the same interview, potentially leaving them in a constant state of flux. It is interesting that participants were able to switch between topics of continuity and change within the interviews, although none specifically spoke about the effects of this tension. One might expect that living with this state of flux would have some sort of impact upon participants, although most participants commented that they were not particularly worried or anxious about their current situation. However, this state of flux might underlie the desire of participants to maintain their lifestyle and activities, in order to prevent the anxieties that could come about if the tension between continuity and change became any greater. There is also the possibility that participants were putting on a 'brave face', and that the doubts that some were harbouring about the future were a sign of the underlying tension and anxiety about potential change, or a widening of the gap between continuity and change. Of course, it is also important to acknowledge that this analysis reflects participants' views on the subject at a single point in time, so might not be an accurate reflection of participants' experiences across a longer period of time.

One interesting aspect of this type of research would be to examine possible gender differences with respect to changes in self and identity. Although a comparative analysis might be more appropriate for addressing this question, there are some differences that are evident from this study. The main difference that has come to light is in the way individuals respond to difficulties resulting from the symptoms of dementia. The men more commonly expressed anger and even aggression towards themselves in response to the symptoms they were experiencing, whereas fewer women spoke about such reactions. Of course, this might be simply because the men were more likely to express such emotions than the women, who might have deemed it inappropriate to respond in such a way, but it did seem that the women were less likely to experience feelings of anger or aggression. Other differences that became apparent were that the men appeared to be more confident about remaining the same as a person, whereas the women more often expressed uncertainty on this issue, and that women were more likely to worry about the effect of dementia on relevant other people, including friends and family, than the men were. This could be due to gender differences in previously defined roles, which might affect how individuals would respond to such a situation. Further research would be helpful in clarifying these potential gender differences.

It is also clear that the findings of this study relate to common models of self and identity used in research focusing on people with dementia. Participants sometimes talked about 'self' as a single entity, and at other times highlighted the possible multi-faceted nature of the construct of self by describing different features of 'self'. This is consistent with previous research, whereby some authors have considered the 'self' to be a single entity (e.g. Beard 2004; Fontana & Smith, 1989), and others have treated the 'self' as though it consists of several components, such as role-identities (e.g. Cohen-Mansfield et al., 2000), self-recognition (e.g. Biringer & Anderson, 1992) or self-knowledge (e.g. Klein et al., 2003). Approaches based on the social constructionist model focus on the use of the first person indexical, interactions with others, and the demonstration of traits and attributes through speech (e.g. Sabat, 2002), all of which were evident in the transcripts, suggesting that the three types of self that make up the social constructionist view of selfhood in people with dementia are evident among the participants in this study. Some participants also talked about roles that they had occupied across their lifespan, some of which were still intact, which relates to the perspective adopted by Cohen-Mansfield et al. (2000). Another

interesting and somewhat debated issue is the relationship between memory and identity. As mentioned previously, although there is a theoretical link between memory and identity, the empirical evidence has been relatively inconclusive (e.g. Addis & Tippet, 2004; Naylor & Clare, 2008). Many participants in the present study described what they perceived as important memories, which were autobiographical in nature, and often appeared to be accompanied by strong emotions, such as intense sadness or excitement. Several participants made a link between a potential worsening of their memory ability and a change in an aspect of their self. Thus overall it is apparent that aspects of many influential models of the self are reflected in the transcripts of the participants in this study, lending some support to these theories, and also adding to them in the sense of examining how these different components of self might be experienced both in terms of continuity or change in the context of progressive cognitive impairment.

Of course, this study was cross-sectional, and only included participants who were in the early stages of dementia, so the results cannot be generalised to how self might be experienced in people in the more severe stages of dementia. It should also be noted that the participants had volunteered to take part in research and might thus represent quite a select group of people, such as those who are motivated to help others. This could mean that participants had characteristics in common, and might not necessarily reflect the general population. It could be that those volunteering to take part in the study were those who had come to terms with their diagnosis and were more confident about engaging with a researcher, having had the time to integrate the diagnosis into their identities. However, this view was not supported by the content of the interviews - participants varied in terms of time elapsed since diagnosis and appeared to be at different stages with respect to accepting their diagnosis of dementia. It is also possible that further interviews with the participants might have led to other relevant remarks regarding the topic in question, although it was felt that participants gave very rich accounts in the first instance that were amenable to a detailed analysis.

It is important to consider the issues of credibility and trustworthiness in qualitative research, such as those described by Elliott, Fischer, and Rennie (1999). In the current study, as described earlier, the two authors considered the fit of the extracts to themes and themes to sub-themes independently, and also returned to three participants and obtained the views of Memory Clinic staff in order to assure that the

analysis represented the experiences of the participants accurately. Finally, it is important to take into account the expectations of the researchers. Both researchers were familiar with working with people with dementia, and had therefore been exposed to previous views regarding changes to the person with dementia - an important point to bear in mind when undertaking the analysis to avoid any bias. It is also noteworthy that the interviewer (LSC) was relatively young compared to participants, and this may have had an impact on how people with dementia interacted with, and related to, the interviewer. However, all participants seemed comfortable talking to the interviewer and were happy to confide in the interviewer regarding topics or incidents which they had not even discussed with their spouses.

In summary, this study represents an original contribution to the literature on how people with dementia experience self, which may be of importance for family, friends, and health professionals to consider. This is the first qualitative group study (as opposed to case studies) to explore specific aspects of self and identity that appear to exhibit both continuity and change at the same time, and to highlight this tension between the persistence of self and possible changes to the self caused by the onset and progression of dementia. Thus although the study supports the persistence of self in people with early-stage dementia, it points towards some of the things that begin to change with the onset and early progression of the disease. Although some work has been conducted with people in the more advanced stages of the disease (e.g. Sabat, 2002; Sabat & Harre, 1992), it would be of interest to perform further thematic studies with people at different stages of dementia, or to follow the group through to the more severe stages of dementia, in order to understand more about how identity changes over time and what effect this has on the person with dementia.

Major themes included the role of others in the participants' lives, as well as the context and lifestyle through which they were living with dementia, and this highlights the potential role for others and for the environment to play a part in maintaining the identity of a person with dementia. These important aspects in the lives of people with dementia may represent an opportunity for intervention. It is quite clear that people are trying to maintain their sense of identity and to carry on with their everyday lives as far as possible, and that maintaining activities and relationships are one key component of maintaining a sense of identity. Therefore it is important to facilitate such activities and relationships with others, and to offer opportunities for people to express and learn how to deal with the different emotions that might result

from attempting to deal with the challenges that dementia poses, for example through support groups (e.g. Snyder, Jenkins, & Joosten, 1997). It is also important for professionals to be sensitive to the needs of people with dementia and to consider ways of supporting their identity in practice, whether this is through a specific intervention or simply in how one chooses to address people with dementia during routine appointments and assessments. For example, it is important to avoid positioning people with dementia in a negative way, such that patients are labelled and assumed to be less competent than their peers, or have their limitations emphasized, rather than their remaining abilities (Kitwood, 1997, Sabat, 2006). This study provides some valuable insights which might be useful when thinking about how best to address difficulties with self and identity experienced by people with dementia in a way that supports optimal well-being.

Chapter 9: Discussion

Discussion

This thesis has tackled the subject of self and identity in people with early-stage dementia through several approaches. A systematic review of existing literature highlighted some of the salient issues in this field that had not previously been addressed by empirical studies. From this review it became clear that defining the self for the purposes of research was an extremely complex issue, which required an in-depth exploration of various models of the self in order to select an appropriate theoretical framework for this study. A further systematic review of existing interventions designed to support self and identity in people with dementia was conducted in order to identify whether there were any gaps in the literature that could be addressed through the current study that would potentially be useful with respect to clinical practice. Five research questions were developed from the information gleaned from these reviews, which were tackled empirically using both quantitative and qualitative methodologies. This chapter will discuss the findings of the current study in relation to existing literature, and will also explore the practical implications of these findings, methodological considerations, and directions for future research.

Discussion of findings in relation to each research question

1. Do people with dementia score differently on measures of identity compared to age-matched people without dementia?

This is one of the first studies to compare people in the early stages of dementia to healthy older people on several measures of identity. Other studies have previously compared these two groups on a single measure of identity, such as self-knowledge (e.g. Ruby et al., 2009) or strength of identity (Addis & Tippet, 2004), but many studies investigating self and identity in people with dementia have not used a control group, which places obvious limitations on the interpretation of results. Only one recent study (Fazio & Mitchell, 2009) measured more than one aspect of self (use of pronouns and attributes in speech, and self-recognition) in both people with dementia and healthy older people.

Given the extensive literature referring to the deterioration in identity experienced by people with dementia (see Chapter 2), it was somewhat surprising to

find that in this study, there were very few differences in identity between people with early-stage dementia and healthy older people matched on age, gender and education. In fact, healthy older people reported higher levels of identity-related distress than people with dementia, even after anxiety was controlled for. The first point to consider in interpreting these findings is that a large proportion of previous literature in this area has focused on people in the more moderate to severe stages of dementia, and typically it is only more recent studies that have focused on people in the early stages of dementia (e.g. Fazio & Mitchell, 2009; Naylor & Clare, 2008; Ruby et al., 2009). This shift in focus to include people in the early stages of dementia in research might reflect the fact that more attention is now being paid to assessing and diagnosing people with dementia in the early stages of the disease (e.g. Kalbe et al., 2004; Mueller et al., 2005). Thus a large population of people in the early or very early stages of the disease is more accessible to researchers currently than perhaps was the case just a decade ago. It might be the case that if identity is affected in people with dementia, then this change might only be seen in the moderate to severe stages of the disease, and thus was not obvious in the sample of people with early-stage dementia recruited for this study. It is also important to note that the relative lack of differences between the groups does not necessarily indicate that neither group has experienced changes in identity. It could be that both groups have experienced changes in identity due to aging (e.g. Baltes & Baltes, 1990; Brandstadter & Greve, 1994; Sneed & Whitbourne, 2005), but that the added dimension of having dementia does not result in additional changes in identity. Thus it should not be assumed that people in the early stages of dementia experience significant changes in identity due to the illness per se. Despite cognitive impairments and resulting changes in lifestyle experienced by some participants as a result of developing dementia, identity appears to remain relatively in line with that of older people without dementia. This is consistent with a recent study that measured different aspects of the self to those targeted in this study (use of personal pronouns and attributes in speech, and self-recognition), and found few differences between healthy older people and people in the early stages of dementia (Fazio & Mitchell, 2009), but contrasts with the difference in strength of identity between healthy older people and people with dementia found in another study (although people with dementia in this study were more impaired than in the present study; Addis & Tippet, 2004).

This is the first study to date to measure, and report differences, in identity-related distress between healthy older people and people with dementia. Potential explanations for the difference in identity distress were considered in Chapter 5, including the possibility that people with dementia might be unaware of changes in identity, or might be unable to update information about the self, which could result from memory difficulties. Previous literature focusing on awareness in people with dementia has tended to investigate memory functioning as the object of awareness (e.g. Clare 2003, 2004, 2010) and suggests that there is a range in the level of awareness expressed by participants in the early stages of dementia, with many participants being able to appraise their memory functioning accurately. Although no research to date has examined awareness of identity in this way, it seems unlikely that the majority of participants would be unaware of changes in their identity to the extent suggested by the results in the current study. Other researchers have put forward an argument that people with dementia are unable to update personal information about themselves, and are therefore not able to update information about their identity. This would again mean that people with dementia would not be aware of changes in their identity, and would therefore be unlikely to experience distress resulting from these changes. However, evidence for an outdated sense of self (excluding evidence pertaining to people with FTD) is currently limited to case study reports with people in the severe stages of dementia (e.g. Hehman et al., 2005; Klein et al., 2003; but see Mograbi et al., 2009, for a comprehensive theoretical argument regarding the relationship between anosognosia and the self). It is also possible that the people with dementia who participated in this study were not representative of the broader population of people with dementia. During the recruitment process for people with dementia, advice was sought from relevant health professionals regarding the suitability of patients for the study, prior to the initial contact between researchers and potential participants, and it is possible that patients with dementia who were also experiencing mood disorders or those who were particularly distressed were ruled out of the recruitment process at this stage. This could have resulted in a group of participants with dementia who were less anxious, depressed, or distressed than would be the case for the broader population of people with dementia. Since healthy older people were not recruited through health services, there was no such screening in this group. As no previous studies have used the Identity Distress Survey with healthy older people or people with dementia, it is not possible to compare the reported scores

to those found in other studies, which might have given an indication of whether the scores in this study were in the range that might be expected for each population. Therefore, without further research, it is difficult to ascertain what might be responsible for this difference in identity-related distress.

There are of course practical implications relating to these findings. It would appear that people in the early stages of dementia are not experiencing changes in identity that are unusual for people in that age range, and as such are probably not in need of interventions aiming to support identity, at least in the early stages of the illness. Older people appear to be experiencing more identity-related distress, but even here, the majority of participants are reporting no distress or a very low level of distress that is not having an impact on daily life. This would suggest that people both with and without dementia should be assessed individually in order to determine whether any intervention is required. Whilst the data suggests that the majority of participants in both groups are not experiencing identity-related distress, or not to the extent that it is having any great impact, there may be a few individuals in the minority who would benefit from some form of intervention.

2. Are different aspects of self and identity associated, or are they independent of each other?

Whilst other researchers have previously suggested measuring several aspects of identity, as opposed to using a single indicator of identity (Klein & Gangi, 2010), this study is the first to actually measure several aspects of identity and examine the relationship between them. The results from Chapter 5 suggest that there are no associations between the different aspects of identity measured in this study (strength of identity, self-knowledge, and role-identities) in either people with dementia or healthy older adults. Additionally, results from Chapter 6 suggest that there is only a very limited relationship between these aspects of identity and autobiographical memory functioning, which was also considered to be an indicator of identity within this study to some extent. These findings support the work of Klein and Gangi (2010), who emphasize the need to consider aspects of identity separately, before examining how these aspects of identity might interact to form a cohesive sense of identity. However, this approach stands in stark contrast to the vast majority of the previous literature in this area. Studies based on the social constructionist framework focus

primarily on the use of language in social interactions, although several studies use more than one indicator of this (personal pronouns, description of personal attributes in speech, the multiple social personae; e.g. Sabat 2002; Sabat & Collins, 1999). Other studies focus on a single indicator of identity and rely on observations relating to this indicator alone, such as work relating to role-identities (Cohen-Mansfield et al., 2000), self-knowledge (e.g. Ruby et al., 2007) and self-recognition (e.g. Grewal, 1994). However, the results from this study suggest that different aspects of identity might be independent of each other, and therefore assuming that a measure of a single aspect of identity reflects the experience of identity as a whole could be misleading.

This finding might also suggest that each aspect of identity could be affected by injury or illness independently of the others. From the current study it appears that in general, identity has not been severely affected by dementia in the participants, so it is not possible to be certain about the potential effects of illness on different aspects of identity. However, taking into account the possibility that different aspects of identity may be underpinned by different abilities (e.g. language and social skills, different aspects of memory functioning), and that these abilities may be affected to differing extents by the onset and progression of dementia, it seems likely that aspects of identity may be affected to differing extents in people with dementia. This would best be determined by a longitudinal study.

On a practical note, this is of relevance to supporting identity in people with dementia (or potentially other illnesses as well) where some sort of intervention appears justified. Some existing interventions target one specific aspect of identity, or identity as a whole (see Chapter 4), when in fact the results from the current study indicate that it might be of value to consider these aspects of self separately. It could be that some aspects of identity deteriorate in people in the moderate to severe stages of dementia, whilst others thrive, and this pattern may also differ across individuals. Therefore improvements might only be seen if the relevant aspect of identity is targeted, or indeed greater improvements might be achieved by targeting several aspects of identity within a multi-component intervention. It would therefore be relevant to assess different aspects of identity on an individual basis, in order to determine exactly what type of intervention or support is required.

3. How do the different aspects of self and identity relate to aspects of cognitive and functional abilities?

There is a strong debate in the literature regarding the importance of cognitive functioning for maintaining a sense of identity in people with dementia. Some researchers argue that identity deteriorates alongside a decline in cognitive functioning (e.g. Cohen & Eisdorfer, 1986; Fontana & Smith, 1989) whilst others have used frameworks for their research that embrace the notion that intact cognitive abilities are not essential for the maintenance of self. This includes the work of Kontos (2004), whose research on embodied selfhood was based on the theory that the body is a fundamental source of self that does not rely upon cognitive abilities. Sabat and Collins (1999), describing the social constructionist framework, contend that any losses in aspects of the self can be traced to dysfunctional social interactions rather than to the neuropathology of the disease itself. The empirical literature that has examined the relationships between cognitive functioning and identity has to date focused primarily on memory functioning, particularly autobiographical memory functioning. Whilst some researchers argue for an association between identity and memory functioning (e.g. Addis & Tippet, 2004; Jetten et al., 2010; Klein et al., 2004), others have found no such link (e.g. Naylor & Clare, 2008). However, no previous study has examined the relationships between identity and other aspects of cognitive functioning, as was the case with this study.

These results, reported in Chapter 6, were confusing in some respects, since both positive and negative associations between aspects of identity and aspects of cognitive and functional abilities were found. Whilst it was possible to justify the positive associations, the negative ones were more difficult to explain. Also surprising, in light of previous literature, was the almost complete lack of relationship between identity and autobiographical memory. Overall, these results do not fully support an association between better cognitive functioning and a stronger sense of identity. Given that no more than 25.4% of the variance of the different aspects of identity could be predicted from aspects of cognitive and functional abilities, it appears that there must be other factors having a large impact on the maintenance of identity. This is consistent with social constructionist and interactionist frameworks, as well as the concept of embodied selfhood. Of course, this study only involved people in the early stages of dementia, and this might have led to a restriction in the range of

scores on the measures of cognitive and functional abilities. Further work with people in the moderate to severe stages might cast light on this issue. Indeed, relevant literature suggests that the identity of people in the more severe stages of dementia is more likely to have deteriorated (see Chapter 2), but this could be for reasons other than deteriorating cognitive functioning. For example, people in the more severe stages of dementia are more likely to be residing in care homes. Perhaps these different living conditions, which must represent a dramatic change from living at home, impact upon identity. Likewise, it might be that other people respond differently to individuals with dementia who have more severe cognitive impairments, and this change in interaction style affects the person's identity, rather than the actual changes in cognitive functioning per se. This would reflect the work of Kitwood (1997) on the importance of interactions for the person with dementia and how negative positioning can impact upon a person's identity.

The lack of relationship between aspects of identity and autobiographical memory warrants further investigation. Previous studies that have used the AMI as a measure of autobiographical memory have also found either no relationship, or a very limited relationship, with identity (Addis & Tippet, 2004; Naylor & Clare, 2008). It is possible that the memories tapped by the AMI are not important for maintaining identity. Many items on the semantic component of the AMI ask for very specific details from different periods of the participant's life, such as previous addresses, the names of teachers from primary school, and dates of relatives' birthdays. Details such as these might have little impact upon a person's sense of identity. Additionally, participants are forced to recall a single episodic memory for each time period. It might be that memories from a certain time period have more significance in terms of their contribution to the experience of identity. The phenomenon of the 'reminiscence bump' suggests that memories from certain time periods in one's life (the second and third decades) might be easier to recall than memories from other time periods, but the reasons for this have not been firmly established. Some researchers have suggested that memories from these time periods might have been particularly influential in the formation of the self (e.g. Gluck & Bluck, 2007; Rathbone et al., 2008). For this reason, it might be that autobiographical memories from this time period are associated with identity, but the design of the AMI means that this potential effect cannot be observed. Future studies might consider asking participants to recall memories that are of particular importance without restricting recollection to a

particular time period. Blavog and Singer (2004) describe ‘self-defining’ memories, and outline a way of measuring the specificity, meaning, content, and affect of such memories. It could be that memories that are defined by participants as being meaningful or emotional are more likely to have an effect on identity, and this might be an interesting direction to pursue in terms of future research.

Without more research, interventions designed to support identity in people with dementia should be cautious about placing the emphasis on supporting autobiographical memory. Existing research has reached opposing conclusions regarding the relationship between autobiographical memory and identity, although this may be due to the different ways in which autobiographical memory has been measured. This indicates that interventions aiming to support identity through reminders or rehearsal of particular autobiographical memories might not necessarily be effective. Certainly, the review reported in Chapter 4 suggests that this type of intervention has had limited success. Further research outlining in more detail the precise nature of the relationship between memory and identity might be valuable for the purpose of developing more effective interventions of this type.

4. How do the different aspects of self and identity relate to mood and quality of life in people with dementia?

Despite the fact that there is a wealth of theoretical literature pertaining to the importance of supporting identity in order to ensure maximum well-being (Ronch, 1996; Dries et al., 2006; Fazio, 2008; George, 1998), there is very little empirical work to support this literature. A number of interventions have been developed with the aim of supporting identity and improving well-being in people with dementia (see Chapter 4), but there is little empirical work linking a stronger sense of identity to improved well-being on which to base such interventions. There is just one previous empirical study to date that directly tackles the relationship between identity and well-being in people with dementia (Jetten et al., 2010). This study concluded that the loss of identity (reported to be a result of a decline in autobiographical memory) in participants with suspected dementia impacted negatively upon quality of life. The current study also examined the relationship between aspects of identity and quality of life, and was the first to explore the relationships between aspects of identity and mood in people with dementia.

The results (reported in Chapter 7) mostly support a negative association between aspects of identity and symptoms of anxiety and depression, and a positive association between aspects of identity and quality of life. This relationship between identity and quality of life supports the findings reported by Jetten et al., (2010). Chapter 7 describes possible reasons for the associations between aspects of identity and mood and quality of life. It is interesting that predictors for improved mood and quality of life that appeared more than once in the three regression analyses include the importance of the family role-identity, and the TSCS physical and personal items subtotals. Previous studies have reported a role for family and social contacts in lowering levels of depression in people with dementia (Cohen-Mansfield, 2005; Drees et al., 2006), and the role of physical activity in reducing anxiety and depression is also well-documented (e.g. Acree et al., 2006; De Moor et al., 2006; Salmon, 2001). Scores on the personal items subtotal may reflect level of self-esteem, which is also known to be related to lower levels of anxiety (e.g. Rosenberg, 1962) and depression (e.g. Battle, 1978). Therefore, it is perhaps not surprising that these aspects of identity predicted some of the variance in mood and quality of life. However, it is also possible that mood in particular affects how people respond to questions about their identity. Whilst existing literature has examined how aspects of identity might predict well-being in different populations (see also Higgins, 1987), the experience of anxiety or depression could impact upon the way that people rate their identity. Since few participants with dementia in this study reported clinically significant levels of anxiety or depression, it is probably not likely that ratings on measures of identity were affected by mood in this way. However, it is worth taking into account that this might be the case in populations with higher levels of symptoms relating to anxiety or depression.

Since aspects of identity explained no more than 25.1% of the variance in these variables, other factors are clearly also important in promoting lower levels of anxiety and depression and maintaining a good quality of life, as would be expected. However, this result is encouraging with respect to interventions supporting self and identity in people with dementia, although as mentioned earlier, this type of intervention might only be beneficial for a minority of individuals in this population. It is worth noting that although the majority of existing interventions focus on supporting autobiographical memory, this was not a predictor for lower levels of anxiety or depression, although better scores on the autobiographical incident section

of the AMI did predict a better quality of life. It might therefore be worth considering how other aspects of identity associated with lower levels of depression and anxiety might be incorporated into such interventions, such as maintaining leisure activities and engaging in activities that might promote physical well-being. These are aspects of identity that could be incorporated into the lives of many older people with dementia, and perhaps could be promoted as a preventative measure to combat the possible effects of dementia on identity, mood and quality of life.

5. *What is the subjective experience of the impact of developing dementia on self and identity?*

The qualitative study, reported in Chapter 8, was conducted with the aim of understanding more about the subjective experience of the impact of developing dementia on the self. Previous qualitative studies conducted with people with dementia have also explored the experience of identity (Beard, 2004; Gillies & Johnston, 2004). Beard used a grounded theory analysis to specifically explore the impact of receiving a diagnosis of dementia on a person's identity, whilst Gillies and Johnston used a comparative analysis to compare the experiences of people with dementia and people with cancer, with respect to the effect of the illness on participants' identities. Other qualitative studies have focused more specifically on coping strategies employed to support self and identity in people with dementia (e.g. Clare, 2003; Pearce et al., 2003). However, there were issues relating to identity in people with dementia that have not previously been investigated through a qualitative analysis. Topics of interest in this study included exploring how people with dementia define themselves when not restricted to set definitions of identity imposed by a quantitative measure (such as those used in Chapters 5-7), gaining an understanding of how people with dementia believe that their identity might be affected by the progression of dementia, and also examining the impact of others on a person's identity. Since the aim of this study was to try to understand how participants with dementia were making sense of the experience of identity, IPA was selected as an appropriate method of analysis. This was because IPA concentrates on exploring the lived experiences of participants and also acknowledges the role of the researcher in interpreting these experiences.

The analysis of the transcripts reflected the tension between continuity and change that all ten participants appeared to be experiencing to some extent with respect to their identities. At times this tension was not described directly through what participants actually said, but was exhibited in other ways. For example, some participants spent a long time thinking about how to respond to questions regarding changes to themselves, and some started a sentence only to correct it several times as their thoughts on the matter changed as they were speaking to the researcher. In some cases participants also expressed confusion or frustration (for example through facial expressions or tone of speech) as they struggled to describe their experiences in terms of either continuity or change. Although these aspects of the interview are less easy to capture when reporting a qualitative analysis through the use of quotations, they are nevertheless important when interpreting the data. It was interesting to compare the way that participants described themselves to the aspects of identity that were targeted by the quantitative studies (i.e. role-identities, self-knowledge, strength of identity, autobiographical memory). On being asked to describe themselves, many participants spoke of various role-identities, personality characteristics, and also highlighted changes in their memory functioning and the impact of this on day-to-day life. This emphasized the relevance of the measures of identity that had been used in the quantitative studies, and thus the ways in which Neisser's model of identity translated into real-life experiences, which supports the choice of theoretical framework for this study.

The qualitative study did support some findings from the quantitative work. The participants mainly described fairly minor changes to aspects of their identities, as opposed to more serious changes that were having a large impact on daily life, although one participant described more severe difficulties. These difficulties were related to a number of factors that appeared to have an influence on the overall experience of identity, including the location of the participant's home and the fact that she was unable to speak the first language of her local community, the fact that she was no longer allowed to drive and felt isolated, and possibly also the fact that she was the most impaired of the participants. This meant that her memory was more severely affected, which led to great difficulties in accurately remembering recent events, such as visits from friends. Whilst on each of three visits she reported feeling very lonely and isolated, and commented that she did not have regular visitors, her husband reported that she received at least two visits per day from friends or

neighbours, and greatly enjoyed these visits. This points to one way in which impaired memory functioning might lead to changes in identity; even though the participant had visitors on a daily basis, her experience was still one of loneliness and isolation, as she was unable to recall such visits and incorporate these experiences into her sense of identity. This example lends some support to theories that point to the importance of the role of autobiographical memory in the maintenance of identity (Conway & Pleydell-Pearce, 2000; Klein et al., 2004). Also, participants often described their identities in the context of things that they could or could not do any more, supporting the earlier suggestion that identity might not necessarily be something 'within' us, but something that is evident in what we actually do. This resonates to some degree with the findings described in Chapter 6, which suggested that maintaining cognitive abilities might not be important for an intact sense of identity, but highlighted the importance of being able to participate in activities of daily living that might also impact upon identity (Gitlin et al., 2008).

As well as providing the opportunity for a closer examination of individual participants' experiences, this study also added to the findings from the quantitative work in other ways. These included exploring participants' emotional reactions to changes resulting from the onset of dementia, participants' expectations for the future with respect to thoughts about how identity might be affected by the progression of dementia, and the ways in which identity is supported through relationships with friends and relatives. Whilst the quantitative work answered research questions that could not have been tackled through qualitative research alone, this study demonstrated the participants' experiences of negotiating both continuity and change in a way that adds meaning to the results from the quantitative studies.

It should be noted that participants who took part in the qualitative study were invited to do so by the researcher. The decision regarding who to ask to participate depended upon several factors, including the participants' ability to communicate well with the researcher and the level of rapport that had been built up over previous sessions, and also practical issues such as whether the participant was willing to give up further time to participate in an additional session with the researcher. Of course, this might mean that the participants who took part in the qualitative study are not an accurate representation of the population of people with dementia as a whole. Some participants from the quantitative aspects of the study were able to answer items from

questionnaire measures when given a number of options, but struggled to express themselves well beyond these tasks, or were reluctant to do so. Some participants experienced difficulties with word-finding which caused them a lot of frustration during conversation, and for this reason did not take part in the qualitative study. This might have left a group of participants who particularly enjoyed social interaction and perhaps were less likely to experience language impairments, which could mean that the results are less applicable to people with dementia who do not fit this profile. It should also be noted that this chapter was written with a view to submit it for publication upon completion. This meant that the researcher had to adhere to a strict word limit, thereby limiting the descriptions of participants and the context that could be provided within the chapter. It is possible that further details of this kind would have been valuable in terms of understanding more about the idiographic nature of the participants and their circumstances.

Practical implications of findings

The main topic of interest regarding the practical implications of these findings concerns how we can support identity in people with dementia where this is deemed necessary. Currently, although policy guidelines promote person-centred care in general (e.g. NICE, 2011), there is no reference to interventions specifically aiming to support identity in people with dementia. As reported in Chapter 4, interventions of this nature are in the early stages of development, and many are poorly designed, making it difficult to determine how successful such interventions are in supporting identity and in improving aspects of well-being. The results reported in this thesis point to several considerations when developing interventions aiming to support identity in people with dementia. The first point to make is that for people in the early stages of dementia, such an intervention may not be required. Given that most participants in this study did not report any identity-related distress or clinically significant levels of anxiety or depression, or differ from healthy older adults on most measures of identity, a formal intervention is probably not necessary for the majority of people in the early stages of dementia. However, there were several people who did report some identity-related distress. For this minority, an intervention may be

appropriate. With this in mind, the next point would be to consider what the aims and the content of the intervention should be. This study suggests that a stronger sense of identity supports lower levels of anxiety and depression and a better quality of life, so the aims of the intervention might be based on this finding, although further research might uncover other benefits of supporting identity. Given that this study shows only a very weak relationship between autobiographical memory and identity, it seems unlikely that an intervention based solely on supporting autobiographical memory functioning would be of benefit. Results from the current study suggest that a better ability to carry out activities of daily living predict a stronger sense of identity, and that better perceived physical functioning and relationships with family promote lower levels of depression and a better quality of life. Although these results require further investigation to clarify the precise reasons for these associations, it might be that identity would be best supported by concentrating on physical and social activities, rather than on autobiographical memory functioning. A meta-analysis of studies involving physical activity with people with dementia (Heyn, Abreu, & Ottenbacher, 2004) suggested that physical exercise increases fitness, physical function, and cognitive function, which in turn could reinforce a person's sense of identity through improving a person's ability to participate in other activities. Whilst there is little research specifically on the effects of social engagement in people with dementia, previous research with older people has noted benefits including lower rates of disability and cognitive decline in people who participate in social events (Bath & Deeg, 2005). Of course, there is also a wealth of literature supporting a link between identity and social interaction in people with dementia (e.g. Sabat & Harre, 1992; Saunders, 1998). Thus both physical and social activities may have the potential to support identity in people with dementia, although further research would be required to confirm this. As demonstrated throughout the thesis, identity and difficulties relating to identity vary from one individual to the next, and it may be that no one intervention will fit all people with dementia in need of such support. It is more likely that interventions will need to be tailored to the individual. It is unlikely that such interventions will be recommended in future policies or guidelines unless robust benefits are observed in terms of improvements in mood and/or other aspects of well-being for a substantial proportion of people with dementia. Of course, further research with people in the more severe stages of dementia is required to see whether this type of intervention would be relevant and beneficial with such individuals.

However, even though specific interventions aiming to support identity do not appear to be required within this population in general, it might nevertheless be worth considering whether it is worth taking measures to prevent a deterioration in identity, particularly if further research suggests that this is likely to occur as the disease progresses. It is worth bearing in mind that improving well-being in people with dementia, which potentially impacts upon well-being in caregivers, may help to delay institutionalisation (Gaugler, Kane, Kane, Clay & Newcomer, 2003), allowing people with dementia to remain in their own homes and with loved ones for longer, and therefore also having a positive effect on the economy. Therefore it might be valuable to encourage people at all stages of dementia to continue participating in leisure activities where possible, and to maintain active relationships with relatives and friends. Other researchers have suggested that identity may be reinforced during mealtimes through the experience of connecting with family members, who honour and support the identity of the person with dementia (Genoe et al., 2010), or through respecting the ‘embodied nature’ of identity through one’s choice of clothing (Twigg, 2010). This might be easier to implement in the home environment, but should also be relevant for those in residential care. The NICE guidelines (2011) refer to protecting the individuality of the person with dementia, sharing life stories, and maintaining relationships with friends, relatives and carers, and also note that preferences, religious beliefs and spiritual and cultural identity should be taken into account. Although this would appear to be in line with the principles of person-centred care, it might be useful for further research to address the effects of such actions and to provide more specific guidelines on how to incorporate these suggestions in the context of everyday care and support for people with dementia.

Methodological Considerations

The suitability of the underlying theoretical framework and terminology

The literature review presented in Chapter 2 highlighted the fact that many previous studies in this area either failed to define ‘self’ or ‘identity’ for the purposes of the

research, or did not explain how the aspect of self or identity measured reflected the theoretical framework or definition of self or identity given. For this reason, a comprehensive theoretical framework was selected as the underlying basis for this study. Neisser's (1988) framework was selected for the reasons described in Chapter 3.

For this study the framework proved useful in several respects. It provided justification for choosing the specific aspects of identity that were explored in this study, and also tied them to a theoretical framework that was based on the developmental histories and pathologies of the self. Since most aspects of identity that have been studied in people with dementia (and those selected for measurement in this study) fell into the 'conceptual self', it was not possible to examine the relationships between the five different selves described by Neisser (1988). However, within the 'conceptual self' it was possible to examine the relationships between the different aspects of identity - something that has not been attempted in previous studies of self and identity in people with dementia. In addition to this, because the aspects of identity were measurable, it was possible to relate them to other relevant variables, such as aspects of cognitive functioning and mood and quality of life. Many other studies have failed to do this because they have used definitions of self that might allow the self to be detected, but not measured (e.g. studies based on the social constructionist model; Sabat & Harre, 1992; Fazio & Mitchell, 2009). As a result of this, the current study was able to contribute to the existing literature in novel ways. Finally, because the aspects of identity used were true to human experience and thus easy to relate to real life, the analyses produced results that have practical implications, as well as providing theoretical insights. Another noteworthy point from Chapter 3 is that it is also possible to relate the findings from this study to findings from other studies, since there is some overlap between the selves described by Neisser and those described by other researchers, thus avoiding previous difficulties where it has proven difficult to integrate results from different studies. Results from this study have suggested a relatively intact sense of identity, and therefore 'conceptual self', as defined by Neisser (1988). This is in agreement with other studies involving people in the early stages of dementia, which used measures of identity that were also judged to reflect Neisser's 'conceptual self' (see Chapter 3).

Probably a more complex issue to tackle was that regarding appropriate terminology. The decision was made to use the terms 'self' and 'identity' interchangeably in this study, because the task of defining each in a way that was consistent with all previous research was extremely challenging, and it was not possible to arrive at a satisfactory solution. Some previous literature has also used such terms interchangeably, along with other terms such as 'selfhood' and 'personhood'. Other studies (e.g. Cohen-Mansfield et al., 2000) have combined the terms and referred to 'self-identity', for example. Most theoretical frameworks in this field refer to 'the self', rather than 'identity', and sometimes 'identity' is portrayed as being an aspect of 'the self'. A look through the reference list is one way to grasp the number of different terms used to refer to, on many occasions, very similar constructs. It would appear to be a very difficult task to resolve the inconsistencies surrounding terminology, and it seems unlikely that so many researchers with differing views will be able to reach a consensus. The only conclusion that is apparent from the experience of reviewing such literature is that whichever term is used should be clearly defined. This has not always been the case in previous literature, but in a field with so many conceptual challenges, clearly defining the terminology used in the research is essential, and possibly more important than deciding which one of the many possible terms should be used to start with.

One difficulty that occurred specifically with this study was deciding how to categorise autobiographical memory functioning for the purpose of the quantitative work. According to Neisser's model, autobiographical memory is an aspect of the 'conceptual self', alongside other aspects of identity. Thus the AMI was included as a measure of identity in Chapter 7. For Chapter 6 the decision was more difficult, because autobiographical memory could technically be classified as both an aspect of identity and an aspect of cognitive functioning. Including the AMI as an aspect of identity here would have meant that the resulting analyses would have entailed predicting autobiographical memory functioning from more general memory functioning, which would not have been particularly helpful in terms of interpreting the results and drawing conclusions from the study. Given previous literature reporting the justifications for a link between aspects of identity and autobiographical memory functioning (e.g. Conway & Pleydell-Pearce, 2000; Klein et al., 2004), it was decided to explore the relationships between identity and autobiographical memory

functioning separately from the relationships between identity and other types of cognitive functioning. In this way, it was possible to examine the relationships of interest without explicitly categorising the AMI as a measure of cognitive functioning or identity. Certainly, there is no ideal solution to this situation, so the decision was guided by the aims of the analysis, the relationships between the variables described in previous literature, and the potential practical relevance of the results in terms of autobiographical memory being an intervention target.

How appropriate was the mixed methods approach?

The topic of self and identity in people with dementia has previously been tackled using both quantitative and qualitative research, and it is clear that both methodologies produce valuable results that contribute to the knowledge base. Although primarily a quantitative study, the qualitative element to the current research project was invaluable. As described earlier, it was especially interesting to see how the outlined definition of identity mapped onto the accounts of identity given by the participants who took part in the qualitative study. Participants spoke freely of the different roles in their lives, the effect of dementia on their memory functioning, the personality traits that they felt defined them, and so on. It was reassuring to see how the underlying conceptual framework and definition of identity was relevant to the daily lives of participants. The qualitative study also added to the findings from the quantitative aspect of the research because it was possible to tackle a wide range of complex issues through interview that was not manageable through the use of questionnaire measures. This included asking participants how they defined themselves and their identity, as opposed to relying on the pre-determined definition of identity used as a basis for the quantitative work, and tackling delicate issues such as participants' expectations for the future. It also provided an account of the tensions between continuity and change in identity-related issues that participants were experiencing, which was not evident from the quantitative work, and gave participants a voice with which to express this in their own words.

The quantitative elements of the study were, of course, also important. Empirical research of this type was essential if progress was to be made regarding the

relationships between identity and the other variables of interest such as cognitive functioning and mood and quality of life. Factors such as these could potentially inform the development of new interventions where relevant and evaluate the value of such interventions in terms of benefits to participants. In addition, quantitative research was the only way to determine the relationships of different aspects of identity to each other, which is an issue relevant to future research in this area.

How appropriate were the measures for people with dementia?

Most of the measures used in this study had either been standardised with older people, or at least used extensively within this population. The majority of the measures had also been used previously with people at different stages of dementia, and were not problematic to administer or for participants to complete. For some measures, possible answers were printed out on cards so that participants were reminded of the choices they could make, and these appeared to be helpful for some participants, whilst others managed without.

In general, participants were able to complete the measures successfully with instruction. The main area of difficulty for participants occurred when they were asked to make a judgement relating to the passage of time. This was especially problematic when asking participants about personality traits they had possessed around a decade ago. Many participants stated that they could not remember, or gave a single answer to all items, stating that overall, they were the same then as they are now. Interestingly, many healthy older people (both informants for participants with dementia and people in the control group for Chapter 5) also responded in this way, suggesting that the task is not just difficult for people with memory impairments. Previous research has reported successful use of this technique (e.g. Klein et al., 2003; Rankin et al., 2005), but in the current study it was decided to use only the current ratings of personality traits in statistical analyses, as it seemed likely that ratings for any other time period might be unreliable. The discrepancy score calculated (between the participant and the informant scores) for this task might also be brought into question, since the final discrepancy score depends upon the informant's judgements of the participant's traits. One previous study (Klein et al., 2003) did tackle this issue

by asking two informants to rate another person known to them both and calculate the agreement between the raters. As the agreement was relatively high, the authors decided that the raters were accurate in their scoring of the participant's traits. Other studies have not questioned the use of this method, but there are fairly consistent findings across different studies suggesting that the method may be fairly reliable (Rankin et al., 2005; Ruby et al., 2007; Ruby et al., 2009).

The only measure in this study that had not previously been used with people with dementia was the Identity Distress Survey (adapted from Berman et al., 2004), which was actually designed for use with adolescents. Although it was adapted for use with people with dementia for this study, and appeared to be suitable for this population, there is no information available on the reliability or validity of the measure for this purpose. Unfortunately, there was no alternative measure that was considered appropriate, and time constraints prevented the development of a new measure of identity distress specifically for this study. Participants seemed to find the items easy to answer, with the exception of the item asking the respondent to state how long he/she had experienced any distress that he/she had reported. Several participants stated that this was difficult to answer, although since many had reported no distress, this was not an issue for the majority. This points to the need to be sensitive to such issues in future studies.

Another consideration in terms of the identity-related measures was that there was not necessarily a particular 'cut-off' score that reflected a 'normal' or 'abnormal' sense of identity, for example with respect to personality self-knowledge or the role-identity measures. This meant that it was important to use a control group so that it was at least possible to make a comparison with people who did not have a diagnosis of dementia. Previous studies have not always obtained data from a control group using these measures (e.g. Cohen-Mansfield et al., 2000), which is limiting in terms of drawing conclusions regarding the persistence of self in people with dementia from the data.

Limitations of the study

In considering the findings of these chapters, it is also necessary to acknowledge limitations of the current study. Firstly, all participants volunteered to take part in the study, and it is possible that those volunteering may have had some characteristics in common. Approximately 170 people with early-stage dementia were invited to participate in the study, giving a response rate of 29.4%. Those volunteering might have been individuals who had had time to integrate their diagnosis of dementia into their identities and were more comfortable with talking to a researcher about this, rather than those who had just received a diagnosis and had not come to terms with it. However, this seems unlikely since some participants had received their diagnosis some years ago whereas others had only been assessed and diagnosed with dementia more recently. It is noteworthy that participants were all of White British origin, and so results cannot be generalised to people from other backgrounds, particularly given that a person's sense of identity may differ across cultures and ethnicities (Iliffe & Manthorpe, 2004). Participants mostly lived in rural or semi-rural locations. This could have had an impact upon identity for a number of reasons. Smaller villages might be seen as more friendly environments, or alternatively might be experienced as being more isolating, depending on the participant and their location, as well as other factors including issues surrounding transport. Also, people with dementia who live in large cities might have more consistent access to resources, which in turn could impact upon identity. Participants also had to have a relative or friend who could provide proxy ratings on some measures, and again this might single out people who have close contacts, and exclude people who do not, which could also have an effect on a person's sense of identity. In addition, some participants were on anti-dementia medications, which might have affected their responses in some way. Such medications may slow down the progression of cognitive impairments, including memory functioning, which may therefore impact upon the expression of identity. Alternatively, the availability of medication for some participants might affect their perspectives of having a sense of control over the illness, which in turn could lead to a different outlook on the future and a sense of hope. These factors could all influence a person's sense of identity.

There were some limitations in terms of the measures used to assess identity and other variables. The study was restricted to measuring certain aspects of identity, as defined by the underlying theoretical framework used as a basis for the study. It is acknowledged that there are other frameworks that may be valuable in conceptualising and measuring aspects of identity, which might include aspects of identity not included in this study. Also, there were limitations associated with the use of the Tennessee Self Concept Scale to measure the strength of identity. Respondents scored more highly for rating each statement as 'always false', or 'always true' with respect to themselves. The total strength of identity score is therefore based on the assumption that people with a stronger sense of identity either completely agree or disagree that each statement reflects themselves. However, it is possible that a participant may believe just as strongly that the statement is neither completely true nor completely false, but selects 'partly true and partly false'. In this situation the participant receives a lower score, despite the fact that their belief about themselves may be just as strong as people who indicate that the statement is 'always true' or 'always false'. This suggests that some participants may have obtained a relatively low score on the TSCS total and subtotal scores when their beliefs about themselves are just as strong and certain as those who scored very highly, and thus these scores should be interpreted with caution. Additionally, whilst this study focused on relationships between identity and mood and quality of life, there are other measures of well-being that might be of interest. The neuropsychological battery used was also relatively brief, and in some cases (for example in measuring executive function) it might have been helpful to use more than one measure of each cognitive function. It should also be noted that not all measures were designed for use with people with dementia, although most had been used with this population, as described above. Given the lack of relationships between autobiographical memory and aspects of identity, in light of the considerable theoretical literature suggesting a close relationship between these variables, it might have been worth considering a different approach to measuring autobiographical memory. It could be that only certain types of autobiographical memory are important for the maintenance of identity, such as 'self-defining' memories (e.g. Blavog & Singer, 2004) that represent important moments or turning points in a person's history. Given the time restrictions of the current study and also taking into consideration the welfare of participants (i.e. the need to avoid

fatigue or distress), it was necessary to limit the measures used to those described, but future research could address these limitations.

Finally, the study only considered people in the early stages of dementia, so the results cannot be generalised to people in the moderate-severe stages of dementia. Existing research suggests that people in the more severe stages of dementia are more likely to experience changes in aspects of their identity (see Chapter 2), so it is important to consider this when interpreting the results. Additionally, since the study was cross-sectional in nature, the results only give a snapshot of how self and identity are experienced at one time point. It is acknowledged that identity might not be experienced as being stable across even short time periods, and that a longitudinal study would be better suited to looking at changes in the experience of identity over time. It is also difficult to ascertain the direction of influence between the key variables in this study. For theoretical reasons, identity was predicted from aspects of cognitive functioning in Chapter 6, and mood and quality of life were predicted from identity in Chapter 7. However, it is possible that these variables influence each other in both directions. For example, whilst aspects of cognitive functioning might predict a person's sense of identity, participants with a stronger sense of identity might be involved in more social and leisure activities that prevent the deterioration of certain cognitive functions. Equally, whilst identity might predict mood in participants, it could also be that mood influences the way that participants report their sense of identity. This should be taken into consideration when interpreting the results.

Directions for future research

Many of the limitations described above could be addressed in future research. Further research needs to be conducted to investigate whether the results can be extended to people of different ethnic groups and those living in different regions. Additional research also needs to be conducted with people in the more severe stages of dementia. Existing research suggests that identity might deteriorate in people in the more severe stages of dementia (see Chapter 2), although working with this population is likely to bring to the forefront different challenges than working with people in the early stages of dementia, especially relating to appropriate measures. It

is likely that some of the measures used in this study would be inappropriate to use with people in the more severe stages of the disease.

Also relevant to studying people in the more severe stages of dementia is the consideration of where such individuals might be residing. It might be of value to examine whether the experience of identity differs in people with dementia who are living in residential care, and the impact that the transition from living in one's own home to living in residential care might have on one's identity. It might also be possible to examine how relationships affect one's sense of identity in this way. For people with dementia moving into residential care, individuals will most likely be moving from their own home, where they may have been living with their spouse or another family member acting as an informal caregiver, to living within a group of people with similar health conditions and having much less direct contact with family members or informal caregivers. This transition would be of interest in terms of the effects it might have on a person's identity. This could be tackled using longitudinal studies, which would also be of great value in exploring other matters of interest in this area. No study to date has measured identity across different time points in people with dementia, and conducting longitudinal research might put researchers in a much better position to understand more clearly the relationships between identity and cognitive functioning, for example.

In addition, there are questions that have arisen from the current study that could be investigated through further research. Chapter 5 highlighted the fact that healthy older adults might suffer from identity-related distress to a greater degree than people with early-stage dementia. Future research could target the possible reasons for this. It is also unclear from the results presented in Chapter 5 whether people with early-stage dementia do not experience changes in identity, or whether these changes are very similar to those experienced in older people without dementia. It would be of interest to compare these scores on the measures of identity to groups of people of different ages, to see whether there is a point where changes in identity begin to occur. The results from Chapter 6 indicate that most of the variance in scores on identity measures is not accounted for by cognitive abilities. Likewise, in Chapter 7, identity only accounts for a relatively small proportion of the variance in mood and quality of life. Therefore, there are many other factors that play a part in how identity is experienced in people with dementia, and how well individuals score on measures of

mood and well-being. It would be of value to investigate which other factors account for the rest of the variance in these cases, and also to consider measuring specific aspects of autobiographical memory to determine whether only certain memories are important in the maintenance of identity.

The current study has clearly provided a starting point for further research. In attempting to answer some important questions, this thesis has generated many more which could be broached through future studies. Some relate to generalisability, such as the need to involve people from different ethnic groups and regions, and at different stages of dementia. Others have been generated directly from the results in the current study, but would also need to be addressed across different groups and situations, as outlined above.

Conclusion

The experience of self and identity in people with dementia has been a topic of interest over recent years, both for theoretical purposes and due to the implications for care and support of people with dementia. Existing literature has already explored the persistence of self and identity in people with dementia. Chapter 2 was the first systematic review of such literature, and identified a number of limitations. This thesis has taken these limitations into account by using a comprehensive theoretical framework of the self, using sufficient numbers of participants to provide robust evidence, and exploring the relationships between aspects of identity and other variables of interest which to date have not been tackled. The results have challenged previous assumptions and some of the theoretical literature, especially with respect to the high levels of identity-related distress found in control participants compared to people with dementia and the relationship between identity and cognitive functioning in people with dementia. The relative lack of an association between autobiographical memory functioning and aspects of identity also raises questions regarding the justification of designing interventions to support identity by supporting autobiographical memory. However, in addressing these issues, this thesis has raised further questions relating to this topic that could be addressed through future research. Of particular importance is determining whether there is a point at which people with

dementia start to experience changes in their identities that are not seen in healthy older people, and thinking about ways of providing support and care that might counteract any negative effects of this. In this way, people with dementia can receive optimum support and remain independent for as long as possible.

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Appendix

Appendix A: NHS Ethical Approval Letter


National Patient Safety Agency
National Research Ethics Service

Pwyllgor Moeseg Ymchwil Gogledd Orllewin Cymru
North West Wales Research Ethics Committee

PRIVATE & CONFIDENTIAL

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24 June 2009

Dear Miss Caddell

Study Title: Self and identity in people with mild and moderate to severe dementia.
REC reference number: 09/WNo01/28
Protocol number: 1

Thank you for your letter of 23 June 2009, 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.

Mental Capacity Act 2005

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005. The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

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>

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
Application	20023414401719a	28 May 2009
Protocol	1	03 May 2008
Participant Information Sheet: Relative: Group 1	2	22 June 2009
Participant Information Sheet: Relative: Group 1 - Superseded	1	05 May 2009
Participant Information Sheet: Relative: Group 2	2	22 June 2009
Participant Information Sheet: Relative: Group 2 - Superseded	1	05 May 2009
Participant Information Sheet: Participant: Group 1	2	22 June 2009
Participant Information Sheet: Participant: Group 1 - Superseded	1	05 May 2009
Participant Information Sheet: Participant: Group 2	2	22 June 2009
Participant Information Sheet: Participant: Group 2 - Superseded	1	05 May 2009
Participant Information Sheet: Supplementary Info Sheet: Group 1	2	22 June 2009
Participant Information Sheet: Supplementary Info Sheet: Group 1 - Superseded	1	05 May 2009
Participant Information Sheet: Supplementary Info Sheet: Group 2	2	22 June 2009
Participant Information Sheet: Supplementary Info Sheet: Group 2 - Superseded	1	05 May 2009
Participant Information Sheet: Nominated Consultee: Group 1	2	22 June 2009
Participant Information Sheet: Nominated Consultee: Group 1 - Superseded	1	05 May 2009
Participant Information Sheet: Nominated Consultee: Group 2	2	22 June 2009
Participant Information Sheet: Nominated Consultee: Group 2 - Superseded	1	05 May 2009
Participant Information Sheet: Personal Consultee: Group 1	2	22 June 2009
Participant Information Sheet: Personal Consultee: Group 1 - Superseded	1	05 May 2009
Participant Information Sheet: Personal Consultee: Group 2	2	22 June 2009
Participant Information Sheet: Personal Consultee: Group 2 - Superseded	1	05 May 2009
Participant Information Sheet: Care Staff: Group 2	2	22 June 2009
Participant Information Sheet: Care Staff: Group 2 - Superseded	1	05 May 2009
Researcher: Checklist for Consent Process	-	06 May 2009
Participant Consent Form: Personal Consultee: Group 2	1	06 May 2009
Participant Consent Form: Participant: Group 2	1	06 May 2009
Participant Consent Form: Nominated Consultee: Group 1	1	06 May 2009
Participant Consent Form: Personal Consultee: Group 1	1	06 May 2009
Participant Consent Form: Participant: Group 1	1	06 May 2009
Participant Consent Form: Participant: Group 1 Time 2	1	06 May 2009
Participant Consent Form: Nominated Consultee: Group 1 Time 2	1	06 May 2009
Participant Consent Form: Personal Consultee: Group 1 Time 2	1	06 May 2009
Participant Consent Form: Participant: Group 2 Time 2	1	06 May 2009
Participant Consent Form: Nominated Consultee: Group 2	1	06 May 2009
Participant Consent Form: Nominated Consultee: Group 2 Time 2	1	06 May 2009
Participant Consent Form: Personal Consultee: Group 2 Time 2	1	06 May 2009
Protocol for protection of vulnerable adults	1	06 June 2009
GPR/Consultant Information Sheets	1	06 May 2009
Interview Schedules/Topic Guides	1	06 May 2009
Questionnaire: Residential/ku sing Care Home Staff: Moderate to Severe	No version	No Date
Questionnaire: Relatives: Moderate-severe	No version	No Date
Questionnaire: Additional alternative measures: moderate/severe	No version	No Date

Questionnaire: Participants: Milogroup	No version	No Date
Compensation Arrangements: UMAL - Bangor University	No version	01 August 2008
Peer Review	No version	22 May 2008
Letter from Sponsor	No version	22 May 2009
Response to Request for Further information	No version	23 June 2009
Investigator CV	No version	08 May 2009
CV of Supervisor	No version	No Date

Statement of compliance

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

After ethical review

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

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

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

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

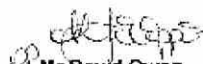
The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

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

09/WNo01/28

Please quote this number on all correspondence

Yours sincerely


Mr David Owen
Chairman

Enclosures: "After ethical review – guidance for researchers"

Copy to: Sponsor's Representative: Prof O Turnbull, Bangor University
R&D office for North West Wales NHS Trust

Chairman/Cadeirydd – Mr David Owen, CBE, QPM

Appendix B: Tennessee Self-Concept Scale 2; Items from the identity subscale.

Physical

- 1. I am an attractive person
- 21. I have a healthy body
- 22. I consider myself a sloppy person (R)
- 29. I am full of aches and pains (R)
- 30. I am a sick person (R)

Moral

- 2. I am an honest person
- 23. I am a decent sort of person
- 31. I am a morally weak person (R)
- 75. I am a bad person (R)

Personal

- 25. I am a cheerful person
- 26. I am a nobody (R)
- 33. I am a hateful person (R)
- 34. I am losing my mind (R)
- 82. I have a lot of self-control

Family

- 3. I am a member of a happy family
- 27. My family would always help me with any kind of trouble
- 35. I am not loved by my family (R)
- 36. I feel that my family doesn't trust me (R)

Social

- 7. I am a friendly person
- 38. I am mad at the whole world (R)
- 39. I am hard to be friendly with (R)

Appendix C: Personality trait list

Please look at each word and decide how well this word describes your personality as it is NOW. Circle the number which refers to the most appropriate answer.

Trait	Not at all 1	A little 2	Quite well 3	Completely 4
Loyal	1	2	3	4
Rational	1	2	3	4
Timid	1	2	3	4
Lazy	1	2	3	4
Cheerful	1	2	3	4
Conventional	1	2	3	4
Modest	1	2	3	4
Cruel	1	2	3	4
Cowardly	1	2	3	4
Pleasant	1	2	3	4
Outgoing	1	2	3	4
Naïve	1	2	3	4
Stingy	1	2	3	4
Co-operative	1	2	3	4
Materialistic	1	2	3	4
Cautious	1	2	3	4
Irritable	1	2	3	4
Sincere	1	2	3	4
Sociable	1	2	3	4
Unpopular	1	2	3	4
Bold	1	2	3	4
Selfish	1	2	3	4
Tolerant	1	2	3	4
Emotional	1	2	3	4
Rude	1	2	3	4
Humorous	1	2	3	4
Excitable	1	2	3	4
Unfriendly	1	2	3	4
Reliable	1	2	3	4
Extravagant	1	2	3	4
Dishonest	1	2	3	4
Adventurous	1	2	3	4
Aggressive	1	2	3	4
Irresponsible	1	2	3	4
Likeable	1	2	3	4
Dominant	1	2	3	4
Talkative	1	2	3	4
Quick-tempered	1	2	3	4
Conservative	1	2	3	4
Passive	1	2	3	4

Appendix D: Identity Distress Survey (adapted from Berman et al., 2004)

To what degree have you recently been upset, distressed, or worried over any of the following issues in your life? Please select the appropriate response.

1. Long term goals? (e.g. long term relationships, long term living arrangements etc)

Not at all	Mildly	Moderately	Severely	Very severely
1	2	3	4	5

2. Friendships? (e.g. experiencing a loss of friends, or change in friends etc)

Not at all	Mildly	Moderately	Severely	Very severely
1	2	3	4	5

3. Religion? (e.g. stopped believing, or changed your beliefs in religion etc)

Not at all	Mildly	Moderately	Severely	Very severely
1	2	3	4	5

4. Values or beliefs? (e.g. feeling confused about what is right or wrong etc)

Not at all	Mildly	Moderately	Severely	Very severely
1	2	3	4	5

5. Group loyalties? (e.g. belonging to a club or group)

Not at all	Mildly	Moderately	Severely	Very severely
1	2	3	4	5

6. Please rate your overall level of discomfort about all of the above issues as a whole (i.e. how bad they made you feel).

Not at all	Mildly	Moderately	Severely	Very severely
1	2	3	4	5

7. Please rate how much uncertainty over these issues has interfered with your life as a whole (e.g. stopped you doing things you wanted to do, or stopped you from feeling happy).

Not at all	Mildly	Moderately	Severely	Very severely
1	2	3	4	5

8. How long (if at all) have you felt upset, distressed, or worried over these issues as a whole?

Never/less than 1 month	1 to 3 months	3 to 6 months	6 to 12 months	More than 12 months
1	2	3	4	5

Appendix E: Extract from themes list for a single participant (with quotes)

I can't remember

I forget things....simple things (7)
now I can't even remember what I'm going to the shops for...(14)
I go out and I get there and I think I'm sure I wanted four things and I can only remember three (17)
by the time I realised that I couldn't find the (?) there was none in the shop, I couldn't remember what else I wanted (56)
It took it out of my head (59)
I'd concentrated so hard on remembering the lard, I forgot what else I wanted...(60)
I can't remember now what I wanted (62)
I know I only wanted a few things but I can't remember what I forgot at all. (63)
especially when we're dancing and I can't remember the steps...(75)
but sometimes no matter what I do, I can't remember em. (91)
now, if you said to me how do you start the foxtrot...I couldn't get up and say well you do this that and the other (95)
when I can't remember what I regard as simple things (419)
it's more personal things that I seem to not be able to remember (798)
little incidents with people's names sometimes...(800)
I could go out and see people that I've known for years, but I haven't seen for a long time, then it'd be Hallo...er...er...is it F (???) y'know? (805)
I can remember the faces but I can't put a name to the face...(811)
sometimes I can't remember where my tools are (838)
I can't remember where I put my tools (903)
sometimes, something'll come up, and I'll think, yeah, and I can't remember the details of something that's happened (1318)
I got to that junction and I thought, I remember being here, I remember walking down that street...but what I was doing there and why I was there I haven't got a clue. But I definitely walked down that street, near the university...and it stood out- the street stood out in my mind. I walked down that street- I walked down that, I walked down this side of the street, not that side of the street, that much I could remember...but why I was in that street, walking down it, and why it stood out, I couldn't remember. (1327)
I'm trying to think, what did I make the other day...(175)
I can't think what it was (178)
Er.....that's not so good...mind you, I don't think there's significant things, there's...y'know, to jump out the same...(1611)

I get angry with myself

I get angry when I forget things....simple things (7)
I really do get angry with myself (10)
very angry with myself (11)
that's what really angers me most (16)
that's when I get really angry with myself (20)
I still get angry...(24)
I get really angry with myself (66)
I try not to get angry but I do. (68)
I really do- really do get angry about it sometimes (434)

I get really angry with myself sometimes, really angry...(404)
I get angry with myself (423)
get angry (426)
that can be quite annoying (813)
then I get annoyed with myself again (904)
If I couldn't do things –if I couldn't get things right I would er, mentally give meself a
good kicking (1714)

More harm than good

I probably do myself more harm than good (8)
I know it doesn't do me any good to get angry (21)
probably (should) cool down and think about it (23)
that doesn't help (74)
that doesn't help (67)
I'll make it worse....(426)
I try not to...(416)
even though I try not to (424)
I know it's probably the worst thing I can do (425)
I try not to (431)
I know it's wrong (416)

It doesn't really bother me

When that happens, I'll go and search and if I can find my tools, say, I'll get on with
it. If I can't I just say to myself, well you can't do it today, you'll have to think about
it another time (911)
it doesn't really bother me because generally the things I want to do can be done
tomorrow anyway, y'know, there's not many things that've got to be done today.
(917)

I work it out in a logical way

make sure that I, I remember things (29)
I try to associate things...(36)
if I want milk, I probably want bread as well...and we might want sugar, so those sort
of things (36)
I will say right, so, I know I want bread, we must want sugar, we definitely want milk
(39)
I work it out in a sort of logical way if I can (42)
by associating things...(43)
if I want, if I want, bread, milk and sugar, if I can remember that I want bread, I
remember milk and sugar (44)
I can work it out that way (47)
I try to work it out in a logical way (48)

I couldn't do that now

I just couldn't do that now...(98)
I just couldn't do it. (99)

We get along really well

I like the people who do the teaching (116)
they're our (?), our sort (119)
we get along really well with them (120)
I've no doubt they'll be here sometime over Christmas (121)
We really do get along with them very well (123)
most of the other people we get along with very well (124)
most people we get along with very well (129)

Our social world

dancing to me has always been a social thing rather than anything else (110)
it's a nice social occasion to go out...(130)
not just learning to dance but a social occasion (132)
meeting people who you regard as friends (133)
it's made our social world that much bigger (151)
every now and again something will come up and it'll be a wedding anniversary or something like that and we'll get invited to their house for a party and that sort of thing (146)
we like company at Christmas (690)
if they don't come here we'll go there (693)
it was regular for us to go into S (town) to see people (522)

Real friends

if you took that rugby out of my life you'd take a heck of a lot of friends away...(337)
a hell of a lot of friends (340)
I know full well I could walk into them in the middle of L (city) and be talking in-we'd be talking in minutes as though we'd seen each other yesterday...real friends. (341)
Real, real old friends (346)
every now and then I'll see something and I think shall I go and I think no, some reunion or something, and I think no because it's a long time since I played and most of the blokes I played with wouldn't be at the reunion, it'd be the people after that...(347)
when it gets summer, we'll get visitors (517)
we're quite popular like that (519)
it's something that you find in friends as well as family (561)
if I went out, and P was there, we'd be talking as though we'd seen each other yesterday, inside of minutes...(1089)
really good friends, real good friends, got on very well. That, to me, has always been important (1092)
I still...have a great- put a great store on real friendship...real friendship. There's not a lot of it about so when you get one or two real friends, that's important...(1272)
great friend, that friendship's been going on for a long long long time. And er, that to me is important. If you haven't got a friend like that...why, y'know? (1283)
that's what I call friendship...(1802)
That's what I call good friendship, y'know, accept that they've got a problem and don't make it worse by telling everybody else. (1808)

Life is much the same

Life is much the same

Life is much the same (RT)
It doesn't make much difference (EB)
A normal life (EB)
It's like nothing's happened (JJ)
It's just carried on the same really (KL)
Life's not been much different (OB)
I don't think much has changed (VB)
No sudden dramatic change (KD)
It did affect me, but not so much now (KL)

You look alright

You look alright (JJ)
We look normal (JM)
She was shocked (JJ)

It's not stopping me

I haven't dropped anything (KL)
We still go out (OB)
I can still do it (VB)
I still do it (KD)
It's not stopping me (MO)
I'm still able to do it (RT)
I'm not embarrassed (MO)

I just carry on

I just carry on (EB)
I've got used to it (EB)
Get on with it (KL)
I just want to keep going (GE)
Just carrying on (JJ)
I'm living with it (RT)

Just accept it

Just accept it (MO)
I accepted it, I had dementia (JJ)
I've gotta accept (VB)
I've got to come to terms with it (RT)
You've got to put up with it (GE)
I've got to pull myself together (MO)

It doesn't worry me

It doesn't worry me (KL)
I refuse to get down (EB)

I'm not too worried (OB)
It doesn't really bother me (VB)
I don't let it worry me (GE)
It doesn't bother me (MO)
I don't let it get me down (RT)
It's not good if you worry (JM)
I don't worry about it (GE)

Just to do with age
I think it's just that (VB)
Just to do with age (GE)
It's part of getting older (KL)

Everybody treats me the same
People are very nice (EB)
They just carry on (EB)
Treats me as normal (EB)
They haven't noticed (KL)
They're still the same towards me (OB)
Everybody treats me the same (GE)
They don't take any notice (GE)
I'm not being treated differently (RT)
They all chatter away (EB)
You haven't changed to us (JJ)
It doesn't seem to affect other people (KL)

We're alright
We're alright (KL)
She puts up with it (KL)
We get by (KD)
He puts up with it (MO)
We get on alright (JM)
You've got to work it out (EB)

I'm still the same person

I'm still the same person
I don't feel any different (EB)
I'm just ordinary (JJ)
I haven't changed (JJ)
It doesn't affect me much (KL)
I don't think my personality has suffered (OB)
I'm the same person I was (OB)
I think it's just stayed constant really (GE)
I'm still the same (VB)
I'm still the same person (KD)
I'm the same old thing (MO)
That's not changed (RT)
I thought the way I think now, then (JM)
You forget you're like it (EB)

That's the sort of person I am

That's the sort of person I am (KD)

That's the sort of person I am (JM)

I think I'm... (KL)

I'm a pretty outgoing bloke (OB)

I'm very friendly (OB)

I'm not aggressive (OB)

They can talk to me (VB)

I think I'm....(MO)

I'll always stay the same

I'll always stay the same

I'll always stay the same (JM)

I think it'll stay (KL)

I don't think I'll change (OB)

Always will (VB)

I can't see me altering (GE)

I'm still going to do everything (RT)

That will never change (RT)

I wouldn't like to change

I wouldn't like to change (GE)

I'm hoping I shall stay the same (EB)

I never want to be like that (VB)

I hope it won't change (JM)

I hope I do (MO)

Life is much the same

Life is much the same

Life is much the same (RT)

it doesn't appear to affect my everyday life...(5)
on the whole, it hasn't affected my life too much. (17)
It's not affecting my way of life very much. (335)
I try and lead and run my life just as it was before (460)
my life is much the same as it was before I had the strokes...I try and keep it that way. (537)
I do everything else as I did it before (539)
apart from my short term memory, my life is about the same (653)
I try to do everything as I've always done it before...(684)
I've had it, what, three years now, or something like that and I don't feel any different than I did three years ago. (670)

It doesn't make much difference (EB)

doesn't make any difference to my life. (39)
I think I carry on just the same way. (278)
I gallantly go around doing everything I used to do (977)
I mean I live such a sheltered life here that it really, really doesn't make any difference. (771)
I'm just living a normal life. (747)
I'm getting on alright (798)
That's alright –that's automatic (513)

A normal life (EB)

I'm just living a normal life. (747)

It's like nothing's happened (JJ)

Now everything's gone back to normal like there's nothing happened...(1030)
Once that stopped, everything went back to n –it's like, it's like nothing's happened (1077)
I still carry on as nothing's happened as such, cos nothing major has happened (705-709)
Nothing major, as yet. (424)
nothing major's changed at the moment has it? (749-750)
There's no major change in my life at the moment...(1192)
now it's a way of life. (963)
nothing major (6-9)

It's just carried on the same really (KL)

it's just er, carried on the same really (family) (357)
I carry on with them you know (hobbies) (367)
I've always had a good sense of humour....(465)

I've always had a good sense of humour, you know, and got on with people...and er, I haven't got any enemies that I know of...(122)
It's always been like that really. (127)
I've always got on with people you know (174)

Life's not been much different (OB)

Otherwise life's not been much different to what it used to be (42)

I don't think much has changed (VB)

no I don't think they have really...(372)
I don't think much has changed at all...(373)
the way we are now, we were then....(392)
very little has changed I would say, in that sense...(393)
no, I don't think a lot's changed in that sense. (394)
I can't say it's changed things much (388)
nothing's changed there...(837)
that's not unusual, it's not changed (850)
we always did (520)
that's normal anyway because my garage isn't exactly organised (840)
I've usually had to- always had to find them anyway...(845)

No sudden dramatic change (KD)

Well they've not changed dramat-, well there's not been any sudden dramatic change in life (6)

It did affect me, but not so much now (KL)

it did affect me, but not so much now (62)
I used to get annoyed with myself...but not so much now (70)

It doesn't make any difference between us (EB)

he doesn't jump about it at all (148)
He just takes it as it is, you know (149)
he's got used to it I think now (269)
he doesn't take any notice of me! (383)
It doesn't -doesn't make any difference between the two of us (497)
Very little that he criticises...(431)
we're quite happy here. Just the two of us (695)
it's not made any difference to the way he carries on...(575)
he doesn't take any notice. (564)
he accepts things I do (799)

We look normal

We look normal (JM)

We look as normal, as normal people, don't we (721)

You look alright (JJ)

you look alright...(876-877)

I don't know how they expect somebody to be...(1220)
Didn't think of you, she was saying, didn't think of you....don't know
how you're supposed to look when you think of er...{laughs}
They can't work out why I went to see the doctor, and I says, well I
couldn't remember...(362-364)

It doesn't seem to affect other people (KL)

And other people don't seem to notice anything, any change, you
know. (560)

It's not stopping me

I haven't dropped anything (KL)

Well, I like to keep things tidy and in order, as regards the garden, you
know, so I do that. I keep that as straight as I can (96)
I carry on with them you know (hobbies) (367)
I do my garden and that you know, outside, and keep things tidy if I
can. (395)
I haven't dropped anything (404)
Yeah, guitar playing, I've been teaching that, and er, and I go every
Friday night to my friend who lives just up the top of town there, we
have a session every Friday night...(368)
I do those yeah. I do loads of them. (puzzles) (389)

We still go out (OB)

We still go out...(46)
I go out a lot with J (daughter), shopping and things like that (130)
I take an interest in all sorts of sports, and er, if there's something on
that I really like, I'll go and see it you know (125)

I can still do it (VB)

If I'm still capable of driving me car, doing my garden, going to the
rugby game, then why should I regard myself as an old man? (287)
I can still dance...not well, M'll (wife) tell you {laughs}...(291)
I can still do it (293)
there's no problems in that sense, I mean basically now it's gardening,
a bit of woodwork when something comes up (789)
occasionally I still have a go at something like that...(795)
that's no problem really (796)
why should I? (287)
I enjoyed it...so why should I stop playing...as long as I was still good
enough to do it, I kept on doing it. (310)

I still do it (KD)

Yeah...not to the same extent by any means, but yes, I still do
it...(580)
I like to do tapestry and needlework and that sort of thing...erm, and I
read the guardian newspaper every day (162)
I like embroidery and tapestry and that sort of thing (43)