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Author:	Gemma Clemerson
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1. Abstract

Developing dementia care services that allow all people with dementia and their carers to live well is a major government target. Knowledge of how people naturally attempt to cope is essential to developing effective services that facilitate adjustment, reduce excess disability and improve quality of life. The purpose of this review was to present and evaluate the research evidence on coping with dementia from the perspective of those diagnosed with the condition. Twenty-one studies were reviewed - nineteen of these adopted a qualitative methodology. Findings were organised according to the focus of coping. Coping with the general experience of living with dementia was found to be a dynamic process that can be influenced by pre-illness personality, spirituality and the responses of others; consistent support for the use of emotion-focused and problem-focused strategies was found. Meaning making was an important strategy used in an attempt to cope with the impact of dementia on self identity whereas practical and visual strategies were used to manage memory loss. To conclude, coping with dementia is a complex and dynamic process that supports current theoretical coping frameworks.

2. Introduction

Dementia is a progressive neurological syndrome associated with deficits in memory, higher order thinking, communication and orientation (Alzheimer's Research Trust, 2010). Age is a known risk factor with 79% of dementia cases accounted for in those aged over 65 years (Department of Health [DoH], 2009). The prevalence of dementias in the UK is expected to double over the next thirty years (DoH); this trend has been associated with factors such as an aging population and the focus on early diagnosis. It is not surprising therefore that improving dementia care is one of the Government's top health priorities (DoH). At present it is estimated that only a third of people with dementia receive a formal diagnosis and specialised care. The National Dementia Strategy was introduced in February 2009 with the aim of developing services that allow all people with dementia and their carers to live well with the condition (DoH). In order to develop good quality services it is imperative to assess current knowledge in the area.

There has been a major shift in the dementia literature over the last twenty years with reduced focus on the biomedical model in favour of a more psychosocial approach (DoH, 2009). In line with this, greater emphasis has been placed on actively engaging individuals with dementia in research rather than relying solely on carer or professional views. Understanding how people cope with dementia is essential to the development of sensitive services and targeted interventions that improve quality of life and reduce excess disability (Clare, 2003).

The importance of understanding coping in dementia is further highlighted when considering the complexity of difficulties experienced by those living with the condition. Recent reviews of research from the perspective of people with dementia (de Boer et al., 2007; Steeman, de Casterlé, Godderis & Grypdonk, 2006) suggest that their experiences are not simply confined to the loss of memory. Dementia has been found to have a major impact on self identity and self-esteem. This has been linked with the pervasive experience of loss such as loss of autonomy and the ability to make decisions, solve problems and complete everyday tasks. People also describe experiencing significant changes in their relationships with others. Socially, relationships appear to suffer due to the feared stigma associated with dementia resulting in intense feelings of isolation. A range of negative emotions are associated with these experiences including anger, sadness, frustration and humiliation. Research suggests that services can intensify negative experiences through the lack of shared information, poor communication of diagnosis and lack of stimulation within day care. Of course, some individuals report positive experiences of services, however these remain in the minority (de Boer et al.)

2.1. Coping

Three theoretical models of coping linked with chronic illness have been highlighted as potentially useful in understanding coping with dementia (e.g. Clare, 2002, 2003; Clare, Goater & Woods, 2006; de Boer et al., 2007). The stress-coping theory (Lazarus & Folkman, 1984), also known as the transactional model of coping, is most commonly referred to in reference to coping with health-related problems. Within the model, stress and coping are

viewed as dynamic and mutually reciprocal (Folkman, Lazarus, Gruen & DeLongis, 1986). Stress is conceptualised as the relationship between the person and their environment that is appraised as a threat to well-being and exceeding personal resources. Coping refers to the person's cognitive and behavioural attempts to manage the discrepancy between the threat and their resources. According to this model, coping has two primary functions: addressing the problem that is causing the distress (problem-focused) or regulating the associated emotions (emotion-focused). They are considered equally effective depending on the environmental demand (problem) and the internal resources of the person experiencing this.

Cognitive beliefs and appraisals are also central to the self-regulation model of adjustment to illness (Leventhal, Nerenz & Steele, 1984). This model suggests that people make sense of illness by developing illness representations – thoughts about the identity, cause, course, cure and consequences of their condition. These guide coping strategies and influence emotional responses and adaptations to illness and go some way in explaining individual differences in the response to ill-health.

The final model of coping is built on a social-constructionist framework (Charmaz, 1987). This suggests that the goal of coping with illness is to develop a preferred (social) identity. This identity may or may not be associated with illness, and is highly influenced by an individual's social context. It is accepted that the preferred identity may change over time in line with health status and the responses of others.

Coping with dementia has been referred to in previous reviews of literature exploring the experience of living with the condition (de Boer et al., 2007; Steeman et al., 2006). Strategies have been categorised into self-protective and self-adjusting (Steeman et al.) or emotion-focused and problem-focused (de Boer et al.). However, it is important to note that coping was not the main focus or aim of these reviews and was therefore not specified in the search terms. Thus it is unlikely that they represent a comprehensive review of the coping literature. Furthermore studies were not critiqued preventing conclusions being drawn on the strongest quality methods. Finally, only papers published up to 2006 were sampled meaning the most recent research, which has built on these previous studies, has not yet been reviewed. These limitations suggest that an up-to-date critical review of coping in dementia is required.

2.2. Aim

The aim of this review is to present and evaluate the research evidence on coping with dementia from the perspective of those diagnosed with the condition. The review is structured according to the focus of coping outcome. As such, findings are presented on how people cope with a) the general experience of living with dementia, b) the impact of dementia on self c) and memory problems. The quality of research is evaluated to assess the strength of conclusions and to identify areas requiring further research. Implications for clinical practice are also be considered.

3. Method

The databases PsychINFO, ovid MEDLINE, British Nursing Index Archive and the Cochrane Library were searched using the free-text search terms "dementia" or "Alzheimer$" with "cope" or "coping" or "adjust$". These were executed as key word and title searches. The search yielded 1, 643 articles. Fifteen of these met the criteria for this review.

Studies were included in the review if they:

1. included participants with a diagnosis of dementia.

2. aimed to explore or were significantly focused on coping from the perspective of the person with dementia.

3. were published in peer-reviewed journals.

4. were available in English.

Studies were excluded from the review if they:

1. focused on coping with dementia in caregivers.

2. focused on coping with dementia purely from the perspective of caregivers or professionals.

3. provided insufficient details to critically evaluate the methodology and/ or findings.

To ensure a thorough approach, the search was re-executed with subject-headed search terms (see appendix B). The reference lists of relevant articles were also searched for further suitable papers. This yielded 5 additional papers that are also included in the review.

To facilitate comprehensive and systematic evaluation, the studies were critiqued using published appraisal tools for qualitative and quantitative research (Critical Appraisal Skills Programme, 2006). All studies were evaluated on the strength and clarity of their rationale; the appropriateness of their chosen methodology, design, sampling, data collection and analysis; the consideration of ethical issues; the reporting of findings; and the theoretical and/ or clinical value of the research.

Issues of validity and reliability were important considerations for the quantitative studies whereas the qualitative studies were evaluated according to their quality. This was assessed against the following criteria:

1. Commitment to rigor – consideration of data saturation, detailed description of analysis and presentation of sufficient data to support findings

2. Transparency and coherence – Were methods (e.g. for recruitment, data collection and analysis) made explicit and well justified? Were participants discussed in context? Were findings presented in a coherent manner?

3. Validity – was triangulation of data or analysis possible? Was the analysis paper trail independently audited?

4. Reflexivity – did the researcher's consider their own influences on the research? Were methods modified during the study?

5. Impact and importance – were the research findings discussed in relation to the original research questions and existing literature?

4. Findings

Twenty-one studies were included in the review, representing nineteen different research samples. The methodological details and participant characteristics, including Mini Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975) scores demonstrating dementia severity are summarised in table 1. Two studies employed quantitative methods; nineteen studies adopted a qualitative approach and represent a variety of qualitative methodologies. All but one of the studies (Gilmour & Huntington, 2005) excluded participants with frontal lobe dementia. This is because of the differences in onset and clinical features associated with this diagnosis. A section on coping with the general experience of living with dementia is presented first as a broad introduction; this includes sub-sections on the use of specific coping strategies, the influence of extraneous factors and the process of coping. This is followed by sections dedicated to coping with the impact on self and coping with memory problems. A summary of the methodological strengths and limitations of studies in each category is displayed in table 2. Studies are presented in descending order of strength with conclusions being based on the strongest available evidence.

4.1. Coping with the general experience of living with dementia

Ten papers presenting research findings on how individuals cope with the general experience of living with dementia are reviewed here. Seven of these employ qualitative methodology (Beuscher & Grando, 2009; Keady et al., 2007; MacRae, 2008; Mok et al., 2007; Ostwold et al., 2002; Robinson et al., 2005; Werezak & Stewart, 2002), two follow a quantitative approach (de Sousa-Talario et al., 2008; Seiffer et al., 2005) and one presents a review of the faith

Table 1. Studies reviewed.

Study and Country	Method & Data	Participants	Diagnosis	Stage/ MMSE[1]
Beuscher & Beck (2008) USA	Literature review	67: 37 Female; 30 Male Aged: not specified	AD	Early-stage
Beuscher & Grando (2009) South America	Qualitative: ethnographic. Semi-structured interviews, observations & field notes	15: 8 Female; 7 Male Aged: 67-91 years	AD	21-26
Clare (2002) UK	Qualitative: Interpretative Phenomenological Analysis (IPA). Separate semi-structured interviews with participants & carers exploring life experiences, self concept, memory & coping	12: 3 Female; 9 Male Aged: 57-83 years	AD	19-29
Clare (2003) UK	As in Clare (2002)	As in Clare (2002)	AD	19-29
Clare, Roth & Pratt (2005) UK	Qualitative: Thematic analysis, application of coping model (Clare, 2002; 2003) & case study analysis. Semi-structured interviews – a 1 year follow-up to Clare (2002, 2003)	As in Clare (2002)	AD	19-29
Clare, Goater & Woods (2006) UK	Qualitative: Content analysis of semi-structured interview data applying model of illness representations.	22: 10 Female; 12 Male Aged: 57-87 years	Non-frontal: AD, AD (n=20) or mixed AD/ vascular (n=2)	16-29

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[1] Current cut-off scores for the MMSE are: normal ≥ 27 mild= 21–26 moderate = 11–20 and severe = ≤10 (Folstein, Folstein, McHugh, & Fanjiang, 2001).

Study and Country	Method & Data	Participants	Diagnosis	Stage/ MMSE
de Sousa-Talarico, Chaves, Nitrini & Caramelli (2008) Brazil	Quantitative: Statistical analysis of correlation between stress, coping & cognitive functioning within and between an experimental & control group	Expt. Group = 30: 21 Female; 9 Male. Aged: 67-89 years. Control Group = 30: 26 Female; 4 Male. Aged: 62-90 years	AD (Expt. Group) No cognitive impairment (control group)	14-28 (AD) 23-30 (control)
Gillies (2000) UK	Qualitative: Thematic analysis of semi-structured interview data exploring experiences of getting older & failing memory	20: 9 Female; 11 Male Aged: 64-89 years	AD (n=9), multi-infarct (n=2), alcohol-related (n=2) or undifferentiated (n=7)	Not specified
Gilmour & Huntington (2005) New Zealand	Qualitative: Thematic analysis of semi-structured interview data exploring memory loss, coping, support & care needs	9: 4 Female; 5 Male Aged: 56-79 years	AD, multi-infarct dementia or frontal dementia (no freq. breakdown)	Not specified
Keady, Williams & Hughes-Roberts (2007) UK	Qualitative: Co-constructed Grounded Theory (GT) using a life story interview & guided autobiography	1: Female Aged 70 years	AD	27
Macquarrie (2005) Canada	Qualitative hermeneutic approach to analysis of semi-structured interview data using a transition interview for people with AD. Two interviews were conducted with each participant & their spouse over 6 months	13: 4 Female; 9 Male Aged: 60-89 years	AD	17-26

Study and Country	Method & Data	Participants	Diagnosis	Stage/ MMSE
MacRae (2008) Canada	Qualitative: symbolic interactionism & phenomenology. Semi-structured interviews with participants only	8: 2 Female; 6 Male Aged: 60-82 years	AD	Early-stage
Mok, Lai, Wong & Wan (2007) China	Qualitative: Phenomenology. Joint semi-structured interviews with participants & their carer/ family member	15: 11 Female, 4 Male Aged: 56-80 years	Dementia (not specified)	Early-stage
Ostwold, Duggleby & Hepburn (2002) USA	Qualitative: Thematic analysis of video-taped 5 minute public speeches on 'how things have been going lately'.	56: gender split not specified	Dementia (not specified)	5-30
Pearce, Clare & Pistrang UK	Qualitative: IPA. Separate semi- structured interviews with participants & their wives (for triangulation exploring social roles, the impact of their (memory) problem & coping	20: Males Aged: 63-84 years	AD	Mean= 24(2002)
Preston, Marshall & Bucks (2007) UK	Qualitative: IPA. Semi-structured interviews with participants (5 also had a spouse present) exploring the challenges of dementia & coping	12: 5 Female; 7 Male Aged: 58-81 years	AD (n=9) Vascular (n=3)	19-28

Study and Country	Method & Data	Participants	Diagnosis	Stage/ MMSE
Robinson, Clare & Evans (2005) UK	Qualitative: IPA. Semi-structured interviews with married couples where one partner had a diagnosis of dementia exploring understanding & responses to developing dementia	9: 5 Female; 4 Male Aged: 68-85 years	AD (n=7) Vascular (n=2)	20-26 Mean = 23
Seiffer, Clare & Harvey (2005) UK	Quantitative: Multiple regression & correlations between self-and carer-report measures of awareness, personality, emotional expression & coping	49: 16 Female; 33 Male Aged: 54-86 years	Non-frontal dementia: AD (n=36), vascular (n=9), Lewy-Body (n=2), mixed AD/ vascular (n=2)	19-25 Mean = 22
Sorensen, Waldorff & Waldemar (2008) Denmark	Qualitative: GT. Semi-structured interviews with participants receiving a structured dementia intervention programme	11: 6 Female; 5 Male Aged: 65-82 years	AD	≥20
Van Dijkhuizen, Clare & Pearce (2006) UK	Qualitative: IPA. Separate semi-structured interviews with participants & their carer (for triangulation) exploring their experience of memory difficulties, relationships & coping	9 Females Aged: 70-86 years	AD	20-29
Werezak & Stewart (2002) Canada	Qualitative: GT. Two semi-structured interviews per participant	6: 3 Female; 3 Male Aged: 61-79 years	AD (n=5) Vascular (n=1)	Early-stage

literature (Beuscher & Beck, 2008). The predominance of qualitative research with broad exploratory aims means that the findings are somewhat varied. However, some consistencies have emerged that allow conclusions to be drawn.

4.1.1. Coping strategies

One finding that has consistently emerged from qualitative and quantitative research is that individuals with dementia use a variety of coping strategies to manage their experience of living with the condition (de Sousa-Talario et al., 2008; MacRae, 2008; Mok et al., 2007; Ostwold et al., 2002). Authors have categorised and labelled groups of similar strategies in different ways including: emotion-focused (e.g. using humour), problem-focused (e.g. keeping notes), cognitive-focused (e.g. denying or minimising symptoms), social-focused (e.g. isolating self) and behavioural (e.g. seeking activities). However, as these strategies are identified in writings of the transactional model of coping (Lazarus & Folkman, 1984), it seems most appropriate in terms of improving clarity and consistency and in understanding the function of different strategies to categorise these into emotion-focused and problem-focused.

Minimising is a popular emotion-focused strategy used to manage the emotional impact of living with dementia (MacRae, 2008; Mok et al. 2007). Individuals have been found to deny or minimise the impact of the condition by viewing memory problems as a part of normal aging, the result of an over-worked brain or God's will (Mok et al.; Ostwold et al., 2002). Other common emotion-focused strategies included: maintaining hope and a sense of humour to provide relief and to reduce stress (MacRae); talking to others and disclosing one's diagnosis to provide a sense of security and facilitate understanding (Mok et al.; Ostwold et

al.); engaging in positive life review to facilitate acceptance (MacRae; Mok et al.; Ostwold et al.); and normalising difficulties to help let go of negative emotions (Mok et al.). Attempts to distract oneself as a way of avoiding the emotional impact of dementia were achieved by focusing on helping others and seeking activities (Ostwold et al.). Problem-focused strategies, designed to directly manage the difficulties caused by living with dementia, included: living day-to-day as a way of taking control over life (MacRae; Mok et al.; Ostwold et al.), self-monitoring, keeping notes, maintaining routine and keeping an active mind (Mok et al.).

As reflected here, the research demonstrated a larger range of emotion-focused compared to problem-focused coping strategies used by individuals with dementia. Indeed a quantitative study of coping (de Sousa-Talarico et al., 2008), found that a group of thirty individuals with AD used more (self-reported) emotion-focused coping than a control group; however, the difference was non-significant. A larger study with more participants would be useful to confirm such findings as the lack of statistical significance here may have been a facet of the small sample employed and the resulting lack of statistical power.

A more robust research finding suggests that the process of selecting different coping strategies may be influenced by individuals' appraisals of their ability to confront or control the difficulties they face. De Sousa-Talarico et al. (2008) found that individuals with higher cognitive functioning in a group diagnosed with AD used (statistically) significantly more problem-focused coping than those with lower cognitive abilities. Thus, in line with the transactional model of coping

it appears that when problems are appraised as outweighing personal resources, people use strategies aimed at regulating the emotions associated with these instead. However, it is difficult to draw strong conclusions from this study alone because nine out of thirty of the AD group were unable to complete the self-report measure due to cognitive deficits.

4.1.2. The influence of extraneous factors

In addition to the research on coping strategies, there is emerging evidence to suggest that coping in individuals with dementia may be influenced by extraneous factors. However, research in this area has, to date, been limited to the influence of others (e.g. Robinson et al., 2005; Van Dijkhuizen et al., 2006), personal faith (Beuscher & Grando, 2009) and pre-morbid personality (Seiffer et al., 2005).

A consistent finding to have emerged from methodologically sound qualitative research is that coping with dementia is a relational process that is highly influenced by the responses of and interactions with significant others. Overprotective or intolerant responses of others towards people's preferred ways of coping can have a negative impact on quality of life and future coping processes (MacRae, 2008; Mok et al., 2007). On the other hand, Pearce et al. (2002) found that others can facilitate positive coping in people with dementia; the wives of male participants with AD were found to protect their husbands from making quick and drastic reappraisals of their abilities thus helping them to regulate their emotional responses. Furthermore, there is evidence to suggest that coping is a reciprocal process between the person with dementia and their significant other in which practical and emotional difficulties are jointly

negotiated to allow both parties to maintain a sense of identity and usefulness (Pearce et al.; Robinson et al., 2005). Relational factors were identified as particularly influential in an IPA study of nine females aged 70-86 years with early-stage AD (Van Dijkhuizen et al., 2006). AD was consistently experienced as a threat to connectedness. When feeling connected through engaging in joint activities or talking to others participants felt better able to accept, problem-solve and normalise their difficulties. However, feelings of disconnection triggered protective strategies such as minimising and avoiding.

Another factor found to have a positive impact on people's ability to cope with dementia is spirituality (Beuscher & Beck, 2008; Beuscher & Grando, 2009). Analysis of interview data, observations and field notes obtained from a sample of fifteen 67-91 year old individuals with a diagnosis of early-stage AD found that spirituality provided a means of connection to important memories, support networks and faith (Beuscher & Grando). Prayer and church activities were important spiritual practices that facilitated acceptance and coping with memory loss and associated emotional difficulties. These findings support and strengthen the conclusions of a recent literature review on the role of faith in coping with dementia (Beuscher & Beck). The review demonstrated that past research in the area was littered with methodological flaws. Papers either: did not state the methodological analyses used to derive themes (Snyder, 2002; Stuckey, Post, Ollerton, FallCreek & Whitehouse, 2002), included participants without a diagnosis of dementia (Katsuno, 2003) or were unpublished (Mantano, 2000). However, the consistency of findings suggests that faith and spirituality may play an important role in coping with dementia; this conclusion may only apply to

Christian, Jewish and Buddhist religions that have been researched to date. Clearly further quality research is required to draw firm conclusions in this area.

Pre-illness personality is the third extraneous factor found to influence coping in individuals with dementia. Research into the relationship between pre-illness personality and avoidant coping (e.g. use of substances, avoiding contact with others and wishing dementia would go away) has found that negative attitudes towards emotional expression predict the use of avoidant coping strategies (Seiffer et al., 2005). These findings emerged from multiple regression analyses on standardised self- and carer-report measures of insight, personality and attitudes towards emotional expression and coping using a sample of forty-nine individuals with non-frontal dementia. Further findings of a significant relationship between high (self-rated) conscientiousness and low awareness of cognitive functioning suggested that highly conscientious individuals may use defensive denial strategies to cope with the impact of dementia. There is a debate in the literature regarding the usefulness of avoidant coping and denial; some research has demonstrated the benefit of this approach particularly in the early-stages of an illness (Glanz & Leerman, 1992) whilst other research has found statistically significant correlations between avoidant coping and long-term psychological distress (e.g. McCaul, et al., 1999). Although these findings emerged from a single study (Seiffer et al.), it was of notable methodological quality with tight controls of potential confounds and adequate power for analysis, thus strengthening the conclusions.

4.1.3. Coping as a dynamic process

Another important aspect of coping with the experience of living with dementia was the changing use of strategies over time. The process of coping has to date been researched using Grounded Theory (GT) (Keady et al., 2007; Werezak & Stewart, 2002) and IPA (Robinson et al., 2005) to analyse interview data. Coping has consistently emerged as a dynamic process that evolves over time in response to changes in symptom awareness (Werezak & Stewart) and clinical presentation (Keady et al.; Robinson et al., 2005; Werezak & Stewart). It has been conceptualised as a process of gradually noticing, making sense of and accepting changes (Robinson et al.; Werezak & Stewart). This was idiosyncratically described as a process of losing, finding and keeping balance in a single-case study of a 70 year old female with AD (Keady et al.).

Typical early coping responses have been identified as seeking a diagnosis (Keady et al., 2007; Robinson et al., 2005; Werezak & Stewart, 2002), searching for a possible cause (Werezak & Stewart) and relying on others (Robinson et al., 2005; Werezak & Stewart). As part of a 5-stage model of adjustment that was developed from the shared experiences of six individuals aged 61-79 years with a diagnosis of AD or vascular dementia, Werezak & Stewart suggested that early coping responses are replaced by attempts to cover up difficulties as the condition becomes more obvious. This is supported by other research demonstrating that people attempt to cover up their difficulties by: denying symptoms (Clare, 2002; Gillies, 2000; Macquarrie, 2005), avoiding thinking about dementia (Clare et al., 2005), hoping that problems are due to something other than dementia (Van Dijkhuizen et al., 2006) and reconceptulaising or diminishing the impact of

symptoms (Clare, 2002, 2003; Gillies; Macquarrie; Pearce et al, 2002; Van Dijkhuizen et al.). Over time, however, individuals continued to adjust and accept the condition through interacting with and receiving support from others, maintaining hope and a sense of humour and living with mistakes (Keady et al.; Werezak & Stewart).

From interviewing couples aged 73-85 years where one partner had a diagnosis of AD or vascular dementia Robinson et al. (2005) found that, beyond the early response to dementia, coping became a joint cyclical process of oscillating between acknowledging changes and recognising resilience. This was managed through the use of family support, focusing on happier times and using relaxation techniques. The process involved joint negotiation and allowed both individuals and couples to maintain and reconstruct their sense of self.

The consistent findings increase the strength of the conclusion that coping with the experience of living with dementia is a dynamic process that evolves over time. However, at this stage the findings may be restricted to coping in individuals between the ages of 61-85 years with AD or vascular dementia as these characteristics dominated the samples.

4.1.4. Evaluation and conclusion

As demonstrated in table 2, research into coping with the experience of living with dementia has, on the whole, been of high quality. The strongest studies (e.g. Mok et al., 2007; Robinson et al., 2005; Van Dijkhuizen et al., 2006) have demonstrated transparency and rigor in data collection and analysis.

Table 2. Summary of methodological strengths and limitations of studies reviewed.

Section	Study	Particular Strengths	Limitations
Coping with the general experience			
Coping strategies	Mok et al. (2007)	Detailed and rigorous analysis Triangulation of analysis Transparent findings supported by quotes Clear contribution (impact)	Poor description of sample (i.e. type of dementia) Limited consideration of reflexivity
	MacRae (2008)	Transparent methods throughout Rigorous analysis process Consideration of reflexivity issues	Aim of research not clearly defined Complicated presentation of findings
	Ostwold et al. (2002)	Rigorous & transparent analysis Triangulation of data & analysis	Importance of themes based on frequency. Some themes supported by small numbers. Little data collected from each ps. (5 minute transcript)
	de Souza-Talarico et al. (2008)	Clear aim & rationale Consideration of impact	Non-matched groups on age Validity: a number of ps. in the experimental group did not complete the measure

Section	Study	Particular Strengths	Limitations
The influence of extraneous factors	Van Dijkhuizen et al. (2006)	Rigorous analysis process Detailed triangulation & audit Findings well situated in existing lit.	Lack of reflexivity Limited sample demographics
	Robinson et al. (2005)	Good coverage of reflexivity Triangulation of analysis & audit Rigorous & transparent analysis	Unclear suitability of sample Limited data (short interviews) Lack of ethical considerations
	Seiffer et al. (2005)	Control of confounding variables Good consideration of impact/ contribution	Possible selection bias as recruited from services Validity issues with self-report & carer measures
	Beuscher and Grando (2009)	Rigorous & transparent methods Clear & coherent findings Triangulation of data collected	Limited consideration of ethics Lack of information on reflexive process
	Beuscher and Beck (2006)	Good rationale Clear aim, method & inclusion criteria	Lacked full critique of studies Limited samples reviewed effecting generalisability/ transferability
Coping as a dynamic process	Werezak and Stewart (2002)	Rigorous analysis Clear & coherent findings Clear contribution (impact)	No information on saturation No triangulation (data/ analysis)

Section	Study	Particular Strengths	Limitations
	Keady et al. (2007)	Rigorous analysis Clear contributions/ impact	Insufficient data collection detail Lack of reflexivity Lack of clarity in findings
Coping with the impact on self	Clare et al. (2005)	Transparent methods Rigorous analysis & coherent findings research required Triangulation of data & analysis	Limited consideration of further
	Clare (2003)	Transparent methods Excellent ethical considerations Triangulation of data & analysis	Lack of sample details (inclusion/ exclusion)
	Clare (2002)	Good consideration of reflexivity Coherent & transparent findings	Little attention to ethics Poor rationale for sample
	Pearce et al. (2002)	Triangulation of data & credibility checks Clear contribution to knowledge (impact)	No rationale for method Reliance on a small number of short supportive quotes
	Preston et al. (2007)	Clear methods throughout Independent audit Little attention to ethics	Poor selection of sample Unclear presentation of findings

Section	Study	Particular Strengths	Limitations
	Macquarrie (2005)	Clear & justified sampling strategy Findings situated in current knowledge	Limited reflexivity Complicated/incoherent findings Lack of audit/ triangulation
	Sorensen et al. (2008)	Rigorous analysis Transparent findings & use of quotes	No information on sample Limited contribution to lit. Poor adherence to methodology (i.e. reflexivity & saturation)
Coping with memory problems	Clare et al. (2006)	Transparent methods & analysis Credibility checks and triangulation Coherent findings & consideration of impact	Lacked consideration of the impact of applying a model to the analysis
	Gilmour and Huntington (2005)	Good consideration of ethics Justified & clear methods Coherent findings	Limited details of analysis process – extraction of themes poorly described
	Gillies (2000)	Appropriate & justified method Good use of supportive quotes	Unclear aim of research Lack of reflexivity, credibility checks, triangulation & rigor

Furthermore credibility of findings has been achieved through the triangulation of different types of data, through independent coding and paper trail audits. Of course, the studies in this section are not completely free from methodological flaws – the limited regard for reflexivity and the lack of clarity in findings being common drawbacks of some of the qualitative papers. However, the consistency of findings across studies suggests that strong conclusions can be drawn.

Based on the evidence in this section, it can be confidently concluded that individuals with dementia use a variety of emotion-focused and problem-focused strategies to cope with their experience of living with the condition. The process of strategy selection may be influenced by appraisals of cognitive capacity with those demonstrating higher cognitive functioning using more problem-focused coping. It may also be strongly concluded that coping is influenced by people's social context and that their interactions with others can either enhance or hinder the adjustment process. Consistent and strong evidence also suggests that coping in individuals with dementia is influenced by personal factors including faith and pre-illness personality. However, further high quality research is required to extend knowledge in these areas. Finally, it seems fair to conclude that coping with the experience of living with dementia is a dynamic process that evolves over time in response to symptom awareness and clinical presentation.

A consequence of the relatively small and homogenous samples used in this research is that the findings may be limited to individuals with early-stage non-frontal dementia – largely AD - who live in the community and are in receipt of

services. Some studies did not state participants' dementia diagnoses, making it difficult to assess the transferability of findings. Clearly further research is required to fully understand coping in individuals with later-stage or more severe dementia, those with a diagnosis of frontal lobe dementia and those living in residential settings.

4.2. Coping with the impact on self

Managing identity has emerged as both a challenge of and a way of coping with dementia (Macquarrie, 2005; Preston et al., 2007). Research has consistently found that individuals with dementia employ a range of coping strategies to manage the impact on self. The findings emerge from the qualitative analysis of semi-structured interviews with individuals with early-stage AD or vascular dementia (Clare, 2002, 2003; Clare, et al., 2005; Macquarrie, 2005; Pearce et al., 2002; Preston et al.; Sorensen et al., 2008).

Research has consistently found that the strategies people use to manage the impact on self fall on a continuum from self-maintaining to self adjusting/ reappraising (Clare, 2003; Clare et al, 2005; Pearce et al., 2002). Other terms used to describe the continuum include: self-protective versus integrative (Clare, 2002), self-continuity versus detachment from self (Preston et al., 2007), passive acceptance versus active adaptations and resistance versus acknowledging (Maquarrie, 2005). Coping has been found to be influenced by individuals' appraisals and awareness of dementia-related difficulties (Clare 2003; Pearce et al.). Appraising memory loss as an expectation of aging can facilitate the

preservation of self although increased awareness of changes and loss however can trigger self-adjusting strategies (Pearce et al.).

Self-maintaining strategies allow individuals to manage their identity by holding on to their existing self-view. Individuals may use a number of strategies to achieve this. For example, individuals may attempt to normalise (Clare, 2003; Macquarrie, 2005; Pearce et al., 2002), minimise (Clare, 2003; Macquarrie; Pearce et al.) or deny (Macquarrie) their difficulties by sticking to routines (Clare, 2002), trying harder (Clare, 2002; Pearce et al.) or taking a break from tasks (Pearce et al.) and using medication to slow cognitive changes (Clare, 2002). On the other hand, self-adjusting strategies are more strongly associated with acceptance and integration of dementia into a changing self-view. Gaining information (Clare, 2002), self-monitoring in order to recognise when adjustments are needed (Macquarrie), developing a fighting spirit (Clare, 2002), focusing on good experiences (Clare, 2002), developing new skills (Preston et al., 2007) and requesting help (Macquarrie; Pearce et al.) were found to facilitate self-adjusting coping. Constructing new roles and downgrading expectations were two additional self-adjusting coping strategies observed in an all male sample (Pearce et al.). Follow-up data demonstrated that coping may become polarised towards self-protective or self-adjusting strategies over time (Clare et al., 2005).

4.2.1. Evaluation and conclusion

In review of the methodology, the studies were of varying quality. The strongest studies demonstrated thorough and rigorous data collection and analyses that

achieved triangulation either through multiple interviews or independent coders and audit (Clare, 2002, 2003; Clare et al., 2005; Pearce et al., 2002). However they sampled a range of ages from 57-83 years (Clare, 2002, 2003; Clare et al.) which may be problematic methodologically as young-onset dementia (under 65 years) has emerged as a unique experience (Beattie, Daker-White, Gilliard, & Means, 2004). Furthermore, coping in other chronic illnesses has been found to be affected by age (de Ridder & Schreurs, 1996) with older adults using more avoidant and emotion-focused coping. The other studies (Macquarrie, 2005; Preston et al., 2007; Sorenson et al., 2008) were limited by factor such as: including participants with secondary chronic illnesses such as heart disease (Preston et al.), failing to provide sufficient participant details (Sorenson et al.) and failing to demonstrate sufficient credibility in findings (Macquarrie) due to a lack of reflexivity and audit checks.

In spite of the methodological limitations, the triangulation of evidence and consistent findings suggest that it is fair to conclude that people employ a combination of self-protecting and self-adjusting coping strategies to protect against the impact of dementia on sense of self. Based on the strongest evidence, coping can become polarised over time and may be influenced by cognitive appraisals and symptom awareness.

4.3. Coping with memory problems

Three qualitative papers offer findings that highlight the ways in which individuals cope with the experience of memory loss in dementia (Clare et al., 2006; Gillies, 2000; Gilmour & Huntington, 2005). The studies collected

interview data from samples of participants with a diagnosis of: non-frontal dementia (Clare et al.); AD, vascular dementia or frontal dementia (Gilmour & Huntington); and AD, multi-infarct dementia, undifferentiated dementia or alcohol-related dementia (Gillies). Data was analysed using thematic analyses (Gillies, 2000; Gilmour & Huntington) and through applying the five dimensions of illness-representations (Leventhal et al., 1984) to content analysis (Clare et al.). Despite the variation in approach and dementia diagnoses, consistent findings emerged from these studies.

This research has consistently found that individuals with dementia use a variety of practical strategies to cope with and compensate for their memory problems. These strategies include the use of written aides such as notes, diaries and labels (Clare et al., 2006; Gilmour & Huntington, 2005; Gillies, 2000); memory cues including using others as proxy memory (Clare et al.; Gillies; Gilmour & Huntington); avoiding or limiting demanding activities (Clare et al.; Gilmour & Huntington); maintaining routines (Gilmour & Huntington); and using medication to slow cognitive decline (Clare et al.). There is also some evidence for the use of intellectual activities such as reading and doing puzzles aimed at improving memory (Gilmour & Huntington). Finally, minimisation and denial of memory problems emerged as strategies used to help manage the emotional difficulties associated with memory loss (Clare et al.; Gillies). Illness representations have been found to influence coping with dementia despite many individuals viewing memory problems as a natural part of aging rather than an illness per se. Participants holding views that nothing can be done about the disease were found to have fewer coping strategies and increased levels of

depression and anxiety (Clare et al.). Potential age differences in illness representations were identified but not discussed in detail, suggesting further research is required to explore coping with dementia across different ages.

4.3.1. Evaluation and conclusion

Individually these studies suffer significant methodological weakness. Clare et al. (2006) presents the strongest evidence detailing clear credibility and transparency in analysis and findings. However, it is likely that the analysis was, at least to some extent, pre-determined by the application of an existing (illness representation) model (Leventhal et al., 1984). The thematic analyses (Gillies, 2000; Gilmour & Huntington, 2005) were applied less rigorously; the abstraction of themes was poorly described (Gilmour & Huntington) and little consideration was given to the heterogeneity of diagnoses within the samples. The practical basis of coping in this section is noteworthy; this may reflect the nature of memory problems or it could be an artefact of the atheoretical nature of thematic and content analysis employed in the studies. Nonetheless, understanding what practical skills people employ to facilitate remembering in dementia is clinically useful in developing interventions such as skills workshops.

Although it is difficult to draw firm conclusions from individual studies due to the methodological limitations, the overall findings were relatively consistent. Thus it may be concluded that individuals use practical techniques such as external memory aids including written notes, limiting activities and relying on others to compensate for and cope with memory loss. Coping may be related to people's appraisals of their difficulties; however, it remains unclear to what

extent people use emotion-focused coping as this only emerged in one study that has significant methodological flaws.

5. Discussion

Developing services that allow people with dementia and their carers to live well with the condition is a top government health priority (DoH, 2009). To ensure that services meet the needs of their users, it is essential to understand how people with dementia naturally attempt to cope with and adjust to the difficulties they experience. The aim of this review was to identify how individuals with dementia cope with their condition by evaluating the research literature from the perspective of persons with dementia. The findings were somewhat varied, which may reflect the predominance of exploratory qualitative studies with broad research aims. Nonetheless there are a number of good quality studies and sufficient consistency in findings to draw reasonable conclusions on the ways in which people cope with the general experience of living with dementia, the impact it has on self identify and symptoms of memory loss.

5.1. Synthesis of findings

It can be concluded with confidence that individuals with dementia use a combination of emotion-focused and problem-focused strategies to cope with the general difficulties raised as a consequence of living with the disease process. These findings are consistent with traditional theoretical models of coping that have been found to apply to other chronic illnesses (i.e. Lazarus & Folkman, 1984). It may be tentatively concluded that choice of coping strategy

is influenced by awareness of cognitive decline with higher functioning individuals using more problem-focused coping than those with lower cognitive functioning; however, this is based on a single study with relatively few participants. A strong conclusion that can be drawn on the basis of the research evidence is that coping with dementia is a complex and dynamic process and that preferred coping strategies may change over time in response to changing health concerns.

Coping with the general experience of living with dementia was consistently found to be influenced by others, supporting social constructionist theories of coping. Although the findings emerged across a number of samples, the influence of others was specifically emphasised in relation to an all female sample. However, more research would be required to make confident conclusions regarding gender differences in coping. The responses of others and their ability to cope with the diagnosis of a loved-one was found to either facilitate or hinder acceptance and coping in the person with dementia, suggesting that coping should be located in an interpersonal framework, as promoted in social-constructionist approaches to health care (e.g. Sabat & Harré, 1992).

More tentative conclusions may be drawn suggesting that coping can be influenced by extraneous factors. Spirituality and religious activities have consistently been found to enhance acceptance and coping, however only one study has been of sound methodological quality (Beuscher & Grando, 2009). Pre-morbid personality traits, illness representations and cognitive appraisals

have also been found to influence coping in individuals with dementia. Individuals with negative attitudes towards emotional expression use more avoidant coping techniques (Seiffer et al., 2005); those who believe that nothing can be done to influence the course of dementia have smaller repertoires of coping strategies and higher ratings of anxiety and depression (Clare et al., 2006). Individuals with a conscientious pre-illness personality may use more denial-focused coping strategies as reflected in the relationship between conscientiousness and unawareness (Seiffer et al.). These findings are based on single yet methodologically robust studies. Thus it is not possible to assess the extent to which the findings can be transferred to other individuals with differing characteristics to the samples (i.e. dementia type and severity). They do however support the finding that coping with illness can vary across individuals and may go some way to explaining the variety of techniques highlighted in this review.

Quality methods, consistent findings and triangulation of data from different qualitative approaches means that confident conclusions can be drawn on how individuals with dementia cope with the impact on self. Strategies used to manage self identity are designed to either facilitate the continuation of self or to facilitate the integration of dementia, including new and lost skills, into and changing view of self. Coping strategies are therefore conceptualised as lying on a continuum from self-protective to self-adjusting or integrative. This is reminiscent of the social constructionist framework of coping with chronic illness presented by Charmaz (1987). In line with this theory, individuals with dementia may initially wish to present themselves with a healthy identity;

however, as their health status changes this may become more difficult prompting a shift in their preferred self. Indeed the best available evidence suggests that coping with the impact of dementia on self identity can become polarised towards self-protective or adjusting processes over time (Clare et al, 2006). These findings counter the debate over whether dementia leads to an inevitable loss of self suggesting that people's self view may shift rather than being wholly lost or preserved. However, the findings are limited to individuals with early-stage dementia and it is possible that identity is further compromised or lost with increasing dementia severity.

Research into coping with memory loss was on the whole less methodologically rigorous. Nonetheless, consistent findings demonstrate that attempts to cope with memory loss were largely practical in nature (e.g. using written memory aids). Individuals may also use some emotion-focused techniques to manage the emotional impact of memory loss although more evidence would be required to confirm this finding across samples. Cognitive techniques in terms of how people conceptualise their memory difficulties (illness-representations) may impact on their response to specific or progressive deficits in memory.

5.2. Methodological critique

This is the first review to focus solely on coping in individuals with dementia and has brought the evidence-base up-to-date. This is particularly important at present because of the increased research interest that has accompanied the Government drive towards better services for people with dementia over recent years. Furthermore this review builds on previous attempts by evaluating

studies and ensuring that conclusions are based on the best available evidence. It also includes findings on the role of faith in coping and coping in a non-Western sample, which have not featured in previous reviews (i.e. de Boer et al., 2007; Steeman et al., 2005).

The findings are limited by the paucity of research in the area. They are based on relatively small homogenous samples representing individuals with a mild-moderate dementia - largely but not exclusively limited to non-frontal dementias - who live in the community and are in receipt of services. This is likely to be a result of the focus on qualitative research and attempts to draw on the experiences of people with dementia rather than relying on carer-report data. Limiting the sample to people who can articulate their experiences remains applicable clinically as these are most likely to be involved in planning their own care (de Boer et al, 2007). However, studies of coping in individuals with later-stage or more severe dementia is required to increase conceptual and theoretical understanding in the area.

The findings are also based largely on qualitative findings. Although this is ideal for researching new concepts and for gaining an understanding of personal experiences quantitative methods also have much to offer this subject area in terms of identifying predictors of coping and the relationships between different factors. The majority of the studies explored coping at a specific point in time by interviewing people with dementia only once. Knowledge of the process of coping over time could be usefully conducted by multiple interviews or employing a longitudinal quantitative design.

The dynamic and contextual nature of coping may suggest that the findings are cohort specific and reflect the current political and social position of people living with dementia. Thus, the experience of coping may change significantly with the developing political context relating to dementia and dementia care. In light of this it would be useful to continue further research with different cohorts of dementia sufferers.

5.3. Clinical implications

The review found that coping in individuals with dementia may be influenced by others suggesting that professional involvement could facilitate adjustment to the condition. Furthermore group-based interventions may be useful whereby people with dementia can take an active role in helping and learning from others. It may also be of benefit to include carers and family members in coping interventions or for interventions to be run specifically for carers as their ability to cope was found to influence coping in the person with dementia.

Another consistent finding was that that coping with dementia can be influenced by various personal factors, suggesting that it is a highly individualised experience. Thus, it will be important clinically for care-plans and service interventions to be individualised to each person considering factors such as personality, awareness, beliefs about the illness and spirituality.

5.4. Further research

The review has highlighted a number of gaps in the literature that require further research. The limited samples studied to date mean that further

exploration of coping in non-community samples, in individuals living alone and in those with more severe/ later stage dementia is required. The majority of the research has identified the conceptual differences between frontal and non-frontal dementias; however, little is yet known about people's experiences of attempting to live and cope with frontal dementia. Furthermore, the review has highlighted a gap in quantitative and longitudinal research which would increase understanding of the process of coping over time and identify possible predictors of positive adjustment. Although two studies have recruited either all female participants or all males little is known about gender differences in coping with dementia. This may be useful to explore using quantitative methods where other factors can be tightly controlled. A major oversight in almost all of the studies has been the influence of age on coping with dementia. Clare et al. (2005) highlighted potential age differences affecting individual illness representations and coping, however this gap in knowledge remains to be addressed in more recent research. Furthermore, early research into young-onset dementia (under 65 years) suggests that it presents unique challenges to individuals (e.g. Beattie et al., 2004), which may impact on coping and adjustment processes. Thus it seems imperative that research into coping in younger people with dementia is conducted.

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7. Appendices.

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Appendix A. Journal Approval Letter and Guide for Authors for Clinical

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Gemma Clemerson
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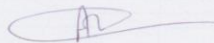Clinical Psychology Unit
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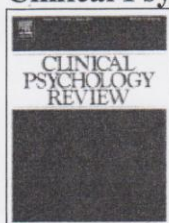
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Appendix B. Subject-heading Search Terms

Subject-heading searches were used to ensure more specific research papers were identified in the literature search.

The search term dementia was exploded to include the following subject-heading terms:

1. Alzheimer's disease

2. Vascular

3. Multi-infarct

4. Dementia with Lewy Body

5. Creutzfeldt Jacob Syndrome

6. Parkinson's disease

7. Pick's disease

8. Semantic dementia

9. Frontal lobe dementia

10. Senile

11. Presenile

The search term coping was exploded to include the following subject-heading terms:

1. Strategies

2. Coping processes

3. Coping behaviour

4. Heuristics

5. Learning

The search term adjust$ was exploded to include the follow subject-heading

terms:

1. Emotional adjustment

2. Resilience

3. Life experiences

4. Social support

Part Two: Research Report

1. Abstract

There is increasing recognition that dementia in people under 65 years presents a unique experience. However, research into coping has failed to reflect this by either ignoring this population or sampling them in conjunction with older adults. This study aimed to explore the experience of living with and adjusting to Alzheimer's disease (AD) in younger life (under 65 years). Semi-structured interviews were conducted with eight participants diagnosed with AD. Interpretative phenomenological analysis (IPA) identified four major themes: 'disruption of the life-cycle', 'identity', 'social orientation' and 'agency'. Most significantly, participants felt too young to develop AD. Loss of skills and social roles were experienced as a threat to self and were associated with loss of agency; feelings of social isolation and disconnection from others were common. Coping emerged as a cyclical process aimed at countering the above experiences. Thus, participants developed ways to take control, reconnect and review life expectations. The threat to self was managed by attempts to preserve their existing identity by denying changes or to re-define self and incorporate their diagnosis. The findings are situated in the human development and life-cycle literature. Implications for further research and clinical practice are discussed.

2. Introduction

2.1. Dementia

Dementia is a progressive clinical syndrome characterised by impairment in higher cortical functioning affecting memory, reasoning, communication and daily functioning skills (World Health Organisation [WHO], 1992). Current prevalence rates stand at an estimated 820, 000 for the United Kingdom (Alzheimer's Research Trust, 2010). However, numbers are expected to rise and the cost of dementia care is estimated to treble to over £50 billion in the next thirty years, making the management of dementia one of the most significant challenges to society (Department of Health [DoH], 2009). Alzheimer's disease (AD) is the most common form of dementia, accounting for over sixty percent of all dementia cases (Alzheimer's Research Trust). Beyond the overwhelming statistics, the impact can be devastating for individuals and families living with the disease.

The last two decades have seen important theoretical and conceptual developments in dementia research and practice. The traditional biomedical view has been challenged with greater emphasis placed on the interaction between biological, psychological and social factors (i.e. Kitwood, 1997; Sabat, 2001; Sabat & Harré, 1992). Kitwood's model of 'personhood' has been highly influential in these developments and has emerged as the accepted blueprint for psychological practice (Guss, Hawkins, Lough & Allen, 2006). The term personhood refers to the fundamental attributes of an individual of which self concept, identity and emotional experience are central. Kitwood argues that the identity of people with dementia is strongly determined by their social

interactions. Thus, in an attempt to preserve personhood and to improve quality of life it is imperative to make the person with dementia the primary focus over the disease process itself.

The shift towards a more holistic view of the person with dementia has been reflected in the emergence of qualitative research exploring individual subjective experiences. Following the trend of other health research, studies have frequently sought to understand how individuals attempt to adjust and cope with the condition (e.g. Pearce, Clare, & Pistrang, 2002; Preston, Marshall & Bucks, 2007; Van Dijkhuizen, Clare, & Pearce, 2006). Research has found that people play an active role in developing coping strategies (Oyebode, Motala, Hardy & Oliver, 2009) that are designed to: manage situations by taking direct action, manage the meaning of situations by reappraising events and manage the symptoms of stress (Keady & Nolan, 1995). Models of coping with AD portray a dynamic process (Werezak & Stewart, 2002) incorporating strategies that lie on a continuum from those designed to minimise the impact of the disease on one end to techniques designed to facilitate acceptance and change on the other (Clare, 2002; 2003). In line with traditional coping theories (i.e. Lazarus & Folkman, 1984), individuals with AD report using a combination of problem-focused and emotion-focused coping (MacRae, 2008; Mok, Lai, Wong & Wan, 2007; Ostwold, Duggleby & Hepburn, 2002). Furthermore, coping has been found to be mediated by personal factors such as premorbid personality (Seiffer, Clare & Harvey, 2005) and faith (Beuscher & Grando, 2009) and the influence of others (Mok, et al.; Pearce et al.; Robinson, Clare & Evans, 2005;Van Dijkhuizen et al.).

Knowledge of coping is considered essential for the development of appropriate and sensitive interventions that maximise quality of life and minimise excess disability (Clare, 2002). The need for such services has become increasingly important due to the trend towards early diagnosis and the development of pharmacological treatments designed to preserve cognitive functioning for longer (Steeman, Dierckx de Casterlé, Godderis, & Grypdonck, 2006).

2.2. Young-onset dementia[2]

Over the last decade there has been increasing interest in young-onset dementia (Werner, Stein-Schachman & Korczyn, 2009). However research remains in its infancy and has largely focused on epidemiological studies (e.g. Keady, 2006) and the clinical or service needs of younger people (e.g. Beattie, Daker-White, Gilliard, & Means, 2004). To date, the psychological research into coping in dementia has either ignored people with young-onset altogether or has sampled them together with those over 65years. However, there are important conceptual and theoretical reasons for studying young people with dementia in their own right.

The life-cycle approach to human development proposes that people pass through a fixed sequence of irreversible stages at different ages in their life. Erikson (1963) suggests that there are eight stages, which each relate to a specific crisis or developmental task. The task for middle adulthood is generativity – building a life, mastering a career and contributing to wider society. Life events such as children leaving home, becoming a grandparent and

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[2] People under the age of 65 years with a diagnosis of dementia.

reaching career goals are typically associated with mid-life (Lachman, 2004).

Mid-life individuals report fewer stressors over which they have no control

(Lachman) and benefit from feeling more settled, having life experience,

financial security, freedom and independence (American Board of Family

Practice, 1990). By contrast, the tasks of old age – typically accepted as

representing people over the age of 65 years – is to review life accomplishments

and manage impending death. Achievements at this stage result in a sense of

personal fulfilment and satisfaction allowing the individual to await death with

integrity.

Erikson (1963) proposed that each stage/ crisis has to be resolved in turn.

However, the onset of a chronic or progressive condition during mid-life forces

people to face the task of old life too soon and potentially prior to successful

completion of the mid-life crisis. As identity during mid-life is defined by work

and relationships with others, this is likely to be threatened by the onset of

dementia (Charmaz, 1983; Coleman, 1996) as people struggle to carry out

conventional roles, tasks and social obligations (Clare, 2003). Thus, the

psychological experience of developing dementia and the coping strategies

developed in response to this may be different for mid-life compared to old age.

Emerging research indeed supports the life-cycle concept and the need to focus

research attention on young people with dementia as they have been found to

represent an important and unique psychosocial and medical position (e.g.

Harvey, Roques, Fox, & Rossor, 1998; Luscombe, Brodaty, & Freeth, 1998;

McLennan, 1999; Sampson, Warren & Rossor, 2004). Younger people

developing the disease are more often in work at time of onset (Beattie et al., 2004). They tend to be responsible for the care of dependent others and have more financial commitments (Alzheimer's Disease Society, 1996). They are more likely to have fewer physical health problems and a greater desire for sexual intimacy than those diagnosed in later life (Cox, 1997, as cited in Beattie, Daker-White, Gilliard & Means, 2002; Sampson et al.). Not surprisingly therefore, higher rates of psychiatric morbidity have been found in younger people with dementia (Gregory & Lough, 2001). As predicted from the life-cycle theories, the emerging American research highlights difficulties relating to identity, roles, social relationships and employment as central in people with young-onset dementia (Harris & Keady, 2004; Harris & Keady, 2009).

In addition to the theoretical and conceptual demands for research focusing on younger people with dementia, there are also clinical drivers. Existing services are often ill-equipped to deal with these needs as younger people are often cared for by older adult services. However, a sense of not belonging has meant that some younger people feel reluctant to engage with such services (Mulligan, 1994; Quin, 1996). Beattie et al. (2002) found that age appropriate services were crucial when they surveyed young people with dementia and their carers. The lack of specialised services may lead to a greater sense of marginalisation and again may therefore impact on people's experience of living and coping with young-onset dementia. Understanding the experiences of younger people with AD may help shape the development of services and improve quality of life for this previously under-researched population.

2.3. Rationale for this study

Dementia presents a growing political and ethical challenge. Further to this, young-onset dementia is emerging as a unique and significant experience that requires further attention in the research literature. The focus on personhood in AD research has provided considerable knowledge on the subjective experiences of people living and coping with this condition in older life. This has been crucial in giving people with AD a voice, beginning to challenge inaccurate social views, improving quality of life and developing services. However, little is known about the subjective experiences of living and coping with AD in people under the age of 65 years. The lack of previous research and the conceptual and ethical drive towards maintaining personhood makes a qualitative approach most appropriate. Such research may be useful in developing services that prevent the further marginalisation of this under served and under researched population.

2.4. Aims of the study

The research aims to explore the subjective experience of living with and adjusting to AD in individuals under 65 years. More specifically it aims to explore in depth:

1. the personal, social and psychological impact of living with AD in younger life

2. how individuals attempt to cope with and adjust to these difficulties.

3. Method

3.1. Methodology

3.1.1. Qualitative

The study aims to explore in detail the phenomena of living and coping with young-onset AD. Three factors were considered when deciding to adopt a qualitative methodological approach: epistemology, technique and theory.

Qualitative research is closely aligned to phenomenological epistemology (Bryman, 1984) in that the meaning of lived experiences forms a central feature of this approach. Qualitative methodology is considered most useful when there is scant research into an area and when not enough is known to derive meaningful hypotheses for empirical investigation (Marshall & Rossman, 1995). Thus, the exploratory nature, along with the focus on understanding individual subjective experiences of AD makes a qualitative approach most appropriate epistemologically (Flick, 1998).

Qualitative methods are also an appropriate choice technically as they are considered to be the most sensitive approach to exploring and understanding the subtle complexities of social and psychosocial phenomena such as dementia (Bryman, 1984). They can facilitate the emergence of novel data that is flexible and responsive to the social context (Mason, 2002). Attempting to apply predetermined quantitative measures to this study may fail to capture the full minutiae of the phenomena and produce results that do not reflect their full social and clinical significance.

Finally, the theoretical drive towards viewing dementia as a biopsychosocial phenomenon further supports the use of a qualitative method. Maintaining 'personhood' (Kitwood, 1997) requires researchers to adopt a holistic and non-reductionist view of people with dementia, which is promoted in qualitative methodology (Mason, 2002). Previous research has demonstrated the feasibility and value of persons with AD being focus participants (e.g. Clare, 2003) and a call has been made for more of this type of research (Allen, 2001, as cited in Beattie et al., 2004).

3.1.2. Interpretative Phenomenological Analysis (IPA)

The decision to use IPA (Smith & Osborn, 2003) followed careful consideration of a number of factors. IPA has been extensively applied to health psychology research and fits well epistemologically with the assumption that verbal dialogues can reflect people's internal cognitions regarding health status and physical change (Smith, 1996). It draws on symbolic interactionism and hermeneutic phenomenology and is therefore committed to understanding human existence and experience through the interpretation of meaning that people negotiate from their interaction with others in their social worlds. It is often applied as a way of obtaining rich accounts of how people make sense of and deal with complex and ongoing health conditions including dementia (Howes, Benton, & Edwards, 2005; Quinn & Clare, 2008) and therefore presents as an appropriate choice for the study. Furthermore its ideographic approach and focus on recruiting relatively small homogeneous samples is well suited to the target sample that is defined by age and dementia type and severity (Howes et al.).

IPA was favoured over other qualitative approaches for epistemological and technical reasons. Grounded theory (Glaser & Straus, 1967) was dismissed for its more positivist stance, which may conflict with attempts to retain personhood; additionally the focus on repeated interviews to reach data saturation may be less suitable for participants with a progressive memory disorder. Other approaches including discourse analysis (Potter & Weatherell, 1995) and narrative analysis focus primarily on the way in which people speak about their experiences and in doing so places great emphasis on vocabulary, pauses and laughter used in conversation (Flick, 1998). This provides a mismatch to the study's aim of exploring individuals' lived experiences and again may be less useful with participants with dementia who may experience fine speech problems (i.e. word finding difficulties). Finally, template analysis (King, 1999) was discounted as a suitable approach to this research due to its focus on comparing the perspectives of different individuals or groups within a specific context (King, 2004).

3.2. Research development

Prior to submission for scientific and ethical review the research protocol was shared with members of a young-onset dementia group run by the Alzheimer's Society. The protocol was amended to reflect their feedback.

3.3. Measures

The Mini Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975) (see appendix B) was administered for the purpose of defining the severity of AD in the sample (i.e. mild-moderate). It is a brief questionnaire

used to screen for cognitive impairment in adults. It contains thirty items grouped into eleven categories including orientation, recall and comprehension. Items are dichotomously scored as correct or incorrect and are summed to a maximum total of thirty. Various cut-off scores have been used to classify the impairment severity with the more recent recommendation that ≥ 27 = normal; 21–26 = mild; 11–20 = moderate; ≤ 10 = severe (Folstein, Folstein, McHugh, & Fanjiang, 2001). The measure has been reported to have good psychometric properties (Folstein et al., 2001).

3.4. Recruitment

Participants were recruited through two NHS sites - a memory service and a young-onset dementia service. In line with the IPA approach, purposive sampling was employed to develop a suitably homogenous sample. To allow for sufficient commonality in experiences, participants were recruited to the study if they were under 65 years, had a medical diagnosis of AD and were British. Additional inclusion criteria were used to restrict recruitment to those considered able to participate in the qualitative aspects of the study – namely the ability to reflect on and verbally communicate their experience. Thus it was considered essential that participants:

1. had been informed of their diagnosis
2. had a mild or moderate level of AD according to their clinician's judgement[3]
3. were able to give informed consent to participate in the study.

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[3] Using the MMSE to determine a mild-moderate AD and ability to engage in reflective conversation was considered. Following consultation with dementia professionals it was agreed that clinical judgement based on the MMSE and combining qualitative information regarding functioning would be most useful as the MMSE is not a measure of verbal ability per se.

To further protect the homogeneity of the sample, individuals with co-existing learning disability or neurological conditions (e.g. Parkinson's disease) were excluded from the study.

Case loads and clinical records were reviewed by teams of clinicians at the participating services to identify individuals who met the inclusion criteria. The research was introduced by clinicians in a standardised way (see appendix C) during routine clinical work. Individuals expressing an interest in participating in the study were provided with an information pack including: an initial contact letter (see appendix D), a participant information sheet (see appendix E), a consent form (for reference) (see appendix F) and a 'consent to be contacted' form (see appendix G). Those wishing to know more or to volunteer to participate returned the consent to be contacted form in a pre-paid envelope and the researcher contacted them by telephone to discuss the research further, answer questions and arrange the interview.

3.5. Participants

The ideographic nature of IPA means that studies usually focus on relatively small and homogenous samples (Smith, Flowers & Larkin, 2009). The final number of participants sampled in this study was determined by the perceived quality and completeness of the data obtained (Morse & Richards, 2002). Data collection continued until the information obtained offered no new concepts or directions in terms of understanding the experience of living and coping with AD. At the point of termination there was considered to be sufficient similarity across accounts and enough detail in the data to describe the phenomena under

study. Published literature and guidelines were used as additional information to guide participant numbers. A review of qualitative research into dementia found that a range of sample sizes have been used in the past, but typically these fall between six and fifteen participants (Steeman et al., 2005). More recent guidance for professional doctorate research suggests that between four and ten interviews are sufficient to allow for successful analysis, reflection and dialogue (Smith et al., 2009).

Eight participants were recruited to the study – seven males and one female. Individual demographics are presented in table 1. All participants were living in their own homes; five lived with their partners, one lived with their daughter and two lived alone. No participants were actively working at the time of interview; six had taken early retirement on medical grounds, one was unable to work due to AD but did not consider themselves retired, and one was still employed but on long term sick leave, which was expected to result in early retirement.

Four people - three females and one male - declined the offer to participate in the study. Clinicians described them as similar to the sample recruited in terms of age and severity of AD. One female was recently diagnosed and declined to participate because she was still attempting to make sense of her diagnosis. The male declined to participate because he had recently contributed to another research project and wanted a break. Other reasons included being anxious about talking to someone new and stress due to illness of a spouse.

Table 1. Table of participant demographics

Name	Age	Months diagnosed	MMSE	Anti-dementia medication
John	63	18	18	Yes
Mark	60	60	18	Yes
George	55	12	18	Yes
Emma	35	18	19	Yes
Peter	59	72	21	Yes
Don	55	12	19	No
Pat	60	24	17	Yes
Malcolm	58	12	21	Yes

3.6. Ethical considerations and approval

Ethical approval was granted by Nottingham Research Ethics Committee 1 (see appendix H). Scientific approval and sponsorship was granted by the University of Sheffield (see appendix I) and governance approval was granted by Rotherham, Doncaster and South Humber Mental Health NHS Foundation Trust (RDASH) (see appendix J).

Careful consideration was given to potential ethical issues. To limit possible distress to participants they were given the option of having a carer present for the interview – advice taken from the young-onset group of the Alzheimer's

Society. In terms of researcher safety, home visits were risk assessed by the referring clinicians and a lone-worker policy was followed.

3.7. Data collection

Data was collected from in-depth semi-structured interviews that were audio-taped. The tapes were transcribed by a professional transcriber who signed a confidentiality form and worked according to set guidelines (see appendix K). All interviews were conducted in one visit and took place in participants' homes. They lasted between 45 and 90 minutes with a mean length of 55 minutes. Four participants chose to have a carer present for the interview although only two carers stayed for the full duration. One participant became tearful during the interview. In this case, the researcher sensitively enquired about their emotional state and gave the participant the option of having a break or terminating the interview – following a short break the participant chose to resume the interview.

The interviews were guided by a schedule that was developed initially from clinical observations and consultation of existing literature. A **pilot interview** was conducted with a female with young-onset AD recruited through the Alzheimer's Society. Feedback was given on the length and flexibility of interview, suitability of questions, prompts and topic areas. The schedule was modified to include a direct question about how people feel having AD at their age and questions to elicit thoughts on the future and use of medication (see appendix L).

The schedule was based on open questions. The researcher adopted a quizzical position and used prompts, probes and clarifying questions to elicit more detail. Interviews began with a question designed to ease people into the interview – the rest of the schedule was applied flexibly to allow for the emergence of novel data and meanings and experiences pertinent to participants. Following initial interviews a circular question asking how individuals believe others view them was included as this emerged as a potentially important issue.

3.8. Procedure

To begin the participant information sheet was talked through and informed written consent was obtained from each participant. The interview was introduced in a standardised way (see appendix L) and a written reminder of the main aims was made available (see appendix M). The interview was then conducted and the audio-recorder was started. Following the interview participants were invited to discuss their emotional responses. No negative affect was reported; three participants explicitly described their participation as a positive experience. Finally, the MMSE was administered; one participant requested that his score was obtained from the memory clinic as he had completed it the previous week.

3.9. Data analysis

The aim of analysis in IPA is to develop an organised, detailed, plausible and transparent account of the meaning of the data (Smith et al., 2009). The process of analysis has been described as an iterative hermeneutic cycle (Smith, 2007)

which proceeds by drawing on the stages outlined below. A worked example of the analysis for an individual case is provided in appendix N.

3.9.1. Initial case-by-case ideographic analysis

In line with the ideographic nature of IPA the data was initially analysed on a case-by-case basis. Thus, each transcript was analysed individually following a process that moved from the general to the specific and from the descriptive to the interpretative.

3.9.1.1. Reading and re-reading

Analysis of each transcript began with the researcher reading the transcript whilst listening to the audiotape of the interview. To become fully immersed in the data the transcript was read and re-read a number of times. In an attempt to bracket off pre-conceptions so they did not dominate the analysis, an analytic diary was used to record initial thoughts on the most striking aspects of the interview and why these may be important (Smith et al., 2009).

3.9.1.2. Initial phenomenological and exploratory coding

In this next stage of analysis the researcher began to underline parts of the transcripts that seemed important. Initial notes and comments were then made on the data (see appendix N). The transcripts were annotated with: a) descriptive codes – key words and phrases that described the content; b) linguistic codes – the type of language used to describe an event or experience (e.g. metaphor or repetition); and c) conceptual comments – questioning the meaning of the data taking coding away from the descriptive and towards the

interpretative. The aim at this stage of analysis was to stay close to the data by using the words of the participants to highlight their most meaningful experiences or concerns. These codes were noted on the right hand margin of the transcript.

3.9.1.3. Interpretative coding

This stage of analysis built on the initial exploratory coding by looking at the transcript as a whole and developing a sense of emerging themes – patterns in topic areas and ways of talking about experiences. The researcher sought similarities and contradictions in individual accounts and referred to psychological knowledge and theory to develop plausible interpretations of the meaning of experiences. This stage required greater creativity and conceptual flexibility. Interpretative codes were noted in the left hand margin of the transcript.

Codes relating to similar experiences were clustered together and sets of super-ordinate and sub-ordinate themes emerged. A table representing these codes was developed for each individual transcript and included excerpts to ensure the codes were grounded in the participants' experiences (see table 1 appendix N).

3.9.2. Integrative analysis across cases

Following case-by-case analysis the table of themes for each participant were compared and contrasted. As similar themes emerged the transcripts were further reviewed for additional evidence to either support or contradict these. At this stage it became apparent that some of the themes from the individual case

analyses were less significant than others or were not shared across the sample. Consequently these were not included in the across case table of themes. Factors that influenced the decision of whether themes were included were: whether the theme represented a shared experience across the sample, however some contractions were initially included where they added to the richness of the data or provided possible prompts for further analysis and interpretation; how significant the themes appeared in the participants' experiences; and whether the themes helped to answer the research aims of developing an understanding of the experience of living with and adjusting to AD in younger life. A master table of the emerging themes was developed (see table 2 appendix N). This formed the most dynamic and interpretative stage of the analysis as the master table was repeatedly revised until a coherent and plausible structure of meaning emerged.

3.9.3 Writing up

Analysis and re-structuring of themes continued throughout the writing-up process as new and meaningful links were discovered in the data (see appendix N). A final table of super-ordinate and sub-ordinate themes was devised (see table 3 appendix N).

The findings will be shared with participants who expressed an interest in knowing the outcome of the study.

3.10. Quality control

In line with the current guidelines of choice (i.e. Elliott, Fischer & Rennie, 1999; Stiles, 1993; Yardley, 2000), the following steps were taken to establish quality and validity:

1. Prior to data collection, the interview schedule was practiced and piloted, allowing the researcher to fully attend to and be led by the participants during interview. As such, the researcher was able to identify and follow up in more detail the experiences most pertinent to each individual, thus establishing *sensitivity and rigor* in data collection (Yardley, 2000).

2. To assess the validity of initial analyses the researcher and research supervisor independently coded the first three transcripts. Similarities and differences were discussed prompting further reflection and refinement of practice.

3. To maximise *transparency and coherence* (Yardley, 2000) participant demographics were detailed and possible interpretations of meaning were evidenced in verbatim accounts (Elliott et al., 1999). To remain thorough, care was taken to include quotes from all participants and to achieve a balance between ideographic and shared phenomena, including phenomenological and interpretative aspects of participants' accounts.

4. A clear paper trail of the research process was developed and **independently audited** by a peer as a way of ensuring a comprehensive, coherent and plausible account of the data was achieved. The audit followed one participant's account from interview schedule to analysis and the final re-writing of results. Discussions regarding the logic of coding, ambiguities and clarity and coherence prompted further reflection and explanation of

interpretations or provision of additional contextual details (i.e. participant demographics) where necessary.

5. *Impact and importance* (Yardley, 2000) of developing interesting and novel findings was achieved by situating the findings in existing literature and outlining the unique theoretical and clinical contributions made in the discussion section.

3.10.1. Reflexivity

In IPA researcher biases are accepted as an integral part of the process as the researcher is likened to a filter through which the lived experiences of participants are conducted and composed (Smith et al., 2009). Therefore the process of reflexivity – reflecting on ways the researcher's values, beliefs and pre-conceptions may have influenced the research – becomes another important quality issue. This process was made transparent through the use of a reflexive journal (see appendix O for examples).

4. Findings

All eight participants were able to offer insights into their experience of living with and adjusting to AD. Four super-ordinate themes emerged from the analysis: 'disruption of the life-cycle', 'identity', 'social orientation' and 'agency'. They incorporate fourteen sub-themes and offer a descriptive label for the cluster of sub-themes that they represent (see table 2). Each super-ordinate theme represents both lived experiences and ways of adjusting to AD. These often lay at opposite ends of a continuum suggesting that adjusting to dementia is an attempt to counteract the experience of living with the condition.

Table 2. Overview of themes.

Super-ordinate themes	Sub-ordinate themes
1. Disruption of the life-cycle	1.1. I am too young
	1.2. Aging
	1.3. Loss of adult competency
	1.4. Contraction of life
	1.5. Reviewing life expectations
2. Identity	2.1. AD: a threat to self
	2.1.1. Stigma
	2.1.2. Loss of self-worth
	2.2. Holding on
	2.3. Redefining self
3. Social orientation	3.1. Disconnection and isolation
	3.2. Reconnecting
4. Agency	4.1. Powerlessness and loss of agency
	4.2. Regaining control

Disruption of the life-cycle is presented first as the most significant theme because it provides the experiential context within which the other themes are embedded. For example, feeling too young to have AD and losing the ability to fulfil expected adult roles impacts on self identity, the experience of connectedness and loss of agency. Beyond this the themes are organised according to a tentative temporal frame with coping emerging as a cyclical process of redefining self, reconnecting with others, regaining control and further reviewing. Themes are illustrated with supportive quotes which have been edited to enhance the readability and to present the participants in the most respectful light (Jones, 1997).

4.1. Disruption of the life-cycle

All participants contributed to this major theme, which draws together issues relating to life course, age and death. For some, the disruption emerged through feeling too young to have AD whilst others felt that the disease had aged them beyond their chronological years. The concept of age and aging emerged as a verbal and relational construct with 'old age' being constructed through the responses of and interactions with others. Participants spoke of losing typical adult competencies and being infantilised by others. The sub-theme contraction of life emerged reflecting the loss of future expectations and an anticipated 'early' death. Finally, reviewing life expectations emerged as a way in which people attempt to cope with the disruption of the life-cycle.

4.1.1. I am too young

Many spoke of experiencing shock and disbelief at their diagnosis. For some this was due to not associating their stage of life with illness: 'At my age I never thought I would ever get anything' (Don. 1.9)[4]. Others were specifically shocked to have developed AD as they felt they were too young: 'because people usually get it in their sixties and seventies…' (Emma. 1.27). This assumption was often reinforced by the responses of others:

> The Doctor says "you are too young to have this" and I said "I am?" LAUGH. (George. 4.94)
>
> […] people think "well you are too young, it can't be". (Malcolm. 3.95)

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[4] References for quotes include participant pseudonym (in text or parentheses), page number and first line number of quote.

The lack of age appropriate services further confirmed their sense of being too young; this was reflected in the following conversations regarding dementia support groups:

> I just thought of things there could be for my age and stuff but all I saw was old people, old men. (George. 33.998)

> If it [the dementia group] was for young people it would be alright but I don't want to be with people who are sixty or seventy. (Don. 14.320)

4.1.2. Aging

The experience of aging emerged as an important theme across a number of interviews. Malcolm linked his sense of aging directly to the onset of AD and the responses of others:

> I feel older and I haven't before at all and it's not so old but then people keep saying I'm old. I'm fifty eight, yes fifty eight and I feel really old, I suppose I am but I have never thought about age before at all.
> (Malcolm. 16.531)

For others, the process of aging was more implied in their inconsistent reference to self. John spoke of being ten years older than his chronological age: 'At least I am seventy-three, I mean sixty-three' (4.79) and Pat made contradictory references to his age, first identifying himself as young: 'I prefer younger [people], about my own age' (16.377) and then switching to an older self view: 'I prefer younger people than you know old fogies like me' (16.382).

The experience of aging was not entirely negative. Creating an identity as an older person, even transiently, allowed people to make sense of developing AD by normalising the life-cycle. Mark who spoke of himself as '…not so young

now…' (9.277) commented: '…everybody gets older and nearer to dementia anyway…' (9.277). Similarly John, who appeared to have a more fluid sense of age said: '…you see you expect to forget a few things don't you when you get to sixty three' (14.323).

4.1.3. Loss of adult competency

A further disruption to the life-cycle was represented in the sub-theme 'loss of adult competency'. This emerged through people's experience of either feeling more 'childlike' due to a loss of skills or being treated this way by others. Thus, it appears the life-cycle is disrupted as people feel unable to meet age-expected roles and consequently feel projected into less independent life stages:

> You know when I am trying to get my coat on and then my wife is trying to get it on for me and I feel like a baby. (Don. 9.197)

> […] there is a couple a couple of doors away who seem to treat me, I don't know, maybe a little bit childlike perhaps. (Malcolm. 4.123)

For some, this was associated with strong negative emotions:

> [when] I can't get my trousers on…it makes you angry, really really angry because you know you can do it…but you can't do it this day. (Pat. 11.253)

> I try for a bit and then I let my wife do it. I get fed up LAUGH. The other day…I wanted my coat on but I couldn't put it on and I just kicked it over there…I end up kicking stuff all over. (Don. 6.134)

4.1.4. Contraction of life

For many, developing AD was experienced as a threat to the life-cycle because it forced them to begin to contemplate death. George and Malcolm spoke of this directly saying: 'When I first got it I thought I was going to be dead soon…'

(George. 4.123) and 'I don't expect to live that long' (Malcolm. 25.840).

Contraction of life was more than dying 'too young' it was also expressed in terms of a loss of expected future life. For many, this included loss of employment as they were forced to take early retirement:

> You think you think that the future would sort of be okay. I always thought I would work until I was sixty five; I am quite physically fit so I had not thought about retiring early or even working beyond it, it just didn't figure. (Malcolm. 7.215)

> […] I was in a position where I should have been trundling along and getting on with it at the end of the day. Then I was told that I wasn't going to work anymore which was a bit of a shock. LAUGH. (Mark. 1.23)

4.1.5. Reviewing life expectations

Reviewing life outlook and expectations was a common way of attempting to manage the disruption to the life-cycle. At a general level some participants made reference to taking on a different view and adjusting their approach to life in an attempt to cope:

> I am just looking at everything from a different point of view. (Malcolm. 9.287)

> I think I have taken on a different style [of coping]…I have to adjust, adjust a little bit here, there and everywhere. (John. 16.385)

Part of the reviewing process was attempting to make sense of how the future may evolve and developing ways of managing the arising thoughts. For many this meant adjusting their life expectations in accordance with a more realistic view. As such, death and further decline became dominant concerns:

> I worry that I won't be here one day, you know, that I'll die.
> (George. 36.1088)

> […] the only thing that what worries me is my future and what is
> going to happen to me. (Emma. 15.448)

In attempting to manage these thoughts some people tried to prevent themselves from thinking about the future, instead taking one day at a time: 'I don't think about it long term, I just take it, take each day by day….' (Don. 21.492). Others tried to stay positive, which for some meant denying further significant decline:

> I think my future will be as basically as what it is now. I shall just get
> up and take the dog for a walk and I suppose we will have the odd
> good thing happening and we will have the odd bad thing happening.
> (John. 23.562).

However, with further reflection it seemed that some participants were working towards resolving these concerns through comparing their situation to others who are either more impaired or who have died younger than themselves. This may be an attempt at making sense of the disruption to the life-cycle:

> […] but then again you think "why has that poor little kid got cancer",
> do you know what I mean? A four year old or a six year old? At least
> I am seventy three, I mean sixty three, so I have had a little bit of an
> innings. (John. 4.77)

> There is no point in worrying [about the future], I have nursed people
> who have died younger than what I am now and I know people who
> have had cancer younger than me and died so I am sort of thinking
> "well, you know if it is ten years more I am going to be late sixties by
> then, that is not too bad sort of thing. (Malcolm. 8.265)

4.2. Identity

A strong theme of identity emerged for all participants. The onset of memory difficulties and diagnosis of AD posed a threat to the way individuals viewed themselves. The struggle to define their identity was linked to the responses of others and the way in which they believed others viewed them. A dichotomy of approaches to managing the threat to identity was described. To regain a stable sense of self some participants either attempted to hold onto their existing self-view or to cut-off from the old self and re-define their identity.

4.2.1. AD: a threat to self

For some, the impact of developing AD was so significant that it was viewed to change their fundamental core or personality: 'I think I thought it [AD] was mainly to do with forgetting but it is a lot more than that. I think it changes you as a person, in fact I am sure it does' (Malcolm. 1.7). Identity was further threatened by the loss of skills, such as dressing and intellectual ability:

> I have got to ask my wife to put my shirts on for me. Oh dear dear…a little thing like that rocks you. (George. 16.475)

> I was forgetting things I should have known. I used to be quite clever then all of a sudden it just seemed to disappear. (Pat. 6.136)

Furthermore, the loss of skills impacted on people's ability to fulfill typical mid-life roles such as caring for the family or leading social groups, which may have also contributed to issues regarding identity:

> Like when they took me on holiday our granddaughter had to take me to the room every day because I would get lost. She was only five and she is taking this bulk home LAUGH. (George. 5.129)

> I cant do things like I used to, like as a Duke of Edinburgh's Award holder, when you are younger you can take yourself anywhere, do anything, anywhere but I have now got the capacity to do things wrong. (Mark. 8.266)

The threat to self also emerged in the context of participants having difficulty identifying with others with AD and struggling to accept their diagnosis as part of themselves. Some participants implied this through their rejection of dementia related activities. Peter spoke of deliberately sitting by the door at a dementia support group, potentially implying his sense of difference or difficulty accepting his diagnosis: 'I sit near the door - it is too warm in there and I sit near the door and he [a peer with dementia] sits at the side of me' (20.474).

4.2.1.1. Stigma

It emerged that self-identity was strongly influenced by the responses of others. All participants contributing to this theme started out from a position of fear that others would view them negatively because of their diagnosis:

> I think people might not want to talk to me because they might think I am thick or summat but I am not. I have got more qualifications than the lot of them. (Emma. 20.612)

> I suppose I was a bit frightened of what people would make of it and think of me. (Malcolm. 7.224)

This had a significant impact on how people felt about disclosing their diagnosis. Some thought that telling others would help them understand whilst others were desperate for people not to find out as they feared being judged or ridiculed. However, most participants who disclosed their diagnosis had positive

responses from others, which helped them to accept their condition as part of who they were:

> I think talking about it helps. I just can't imagine having to be around people who just didn't want to know, I think that could be really, really awful but people are supportive. (Malcolm. 8.246)

> I didn't want to tell anybody, I don't know why…But it was getting bad [at work], people were reporting me for doing things wrong…Then the men at work, the nurses and everybody, when they knew what I had got they were all rallying around. They were quite good. (Don. 16.367)

Emma on the other hand experienced negative responses from others, which further impacted on her sense of self and self-esteem, which prevented her from making links with others and increased her sense of isolation:

> Some people just make it tough, one of the women who I went out with has been telling everyone that I have got Dementia. (Emma. 8.238)

> I don't want to go out on my own… I know where I am going but it is just that I don't want anyone to say anything about me. (Emma. 11.324)

4.2.1.2. Loss of self-worth

The experience of living with AD was found to have a negative impact on people's self-worth. For some, simply having the disease made them question their worth: 'I don't feel as confident perhaps. I feel lesser, smaller because of it in a way.' (Malcolm. 15.494). Others linked this to specific skill deficits and the responses of others:

> […] you feel like, well I must be useless because I can't even write my name and I used to do it regularly, you know, three months ago. (Pat. 14.333)

It [being diagnosed with AD] is just like losing your dignity really and people look at you in different ways and you know, sometimes it can be hard. (Emma. 25.773)

4.2.2. Holding on to self

One way in which participants aimed to regain a stable sense of self was by holding on to their existing self concept:

[…] the past becomes more important because you want to cling on to who you are so things in the past perhaps seem more important than they did. (Malcolm. 13.425)

This was attempted using techniques such as minimising past skills and placing greater importance on preserved skills, adjusting to and compensating for losses and directly denying change:

It was quite hard really [giving up driving], but having said that I have had a very strange driving career…and my abilities were never as good as a lot of people. (Mark. 14.449)

You see I'm quite capable. I get the dog now and go for a walk say 15 mile and I can find my way home. I don't have to stop somebody and say can you take me home I don't know where I live…Basically I'm doing everything I want to do. (John. 24.590).

I am still doing everything that I was doing before. (George. 11.314)

Holding on to their sense of self could be interpreted as an attempt to reduce the discrepancy between past and present capabilities and to thus limit grieving for the 'lost self'. Adopting this approach however appears to limit the extent to which individuals could integrate AD into their identity. Thus, it may be assumed that further decline could continue to threaten their sense of self over time.

4.2.3. Redefining self

Conversely, a sub-theme of redefining self also emerged as a way of re-stabilising self identity. This seemed to represent a process that allowed participants to move towards identifying with their diagnosis and achieving a potentially more robust sense of self in light of possible future decline. For Peter this process began with a purposeful cutting off from the old self: 'Your past life is past. That is gone now - just forget it' (22.516). Again this could be interpreted as a function for reducing grieving for the past self, however, it appears to differ from the process of minimising losses and holding on because it highlights rather than denies changes or loss.

Reconceptualising AD was a common feature of the process of redefining identity. For example, George reflected on his experience of beginning to adjust his view that only 'old' people develop AD: '[we told the neighbours what it was] I said its Alzheimer's. He said "you are joking" I said "there is young kids getting it and all sorts, its not just for old people anymore".' (George. 2.51)

A number of participants spoke about seeking knowledge to help them learn about AD as part of the reappraisal process:

> I do try to find out a lot about it [AD] and there is a lot on-line and sometimes you think "yeah, I understand that." (Malcolm. 24.784)

> I have read about it and always kept up with it as well. (Emma. 1.28)

This new understanding appeared to help individuals move closer to identifying with the disease and beginning to incorporate it as part of their self view. Some spoke of this directly saying: 'It is part and parcel of who I am now' (Peter.

21.490) whereas others suggested this integration through their increased willingness to attend and belong to the dementia support groups: 'I would like to go one day [to the group] and just sit down one day with them all…' (George. 32.982).

A number of participants contributed to both sides of the dichotomy of holding on and redefining self. Thus, these sub-themes may indeed represent a temporal process whereby holding on represents an early response to the threat to self followed by a process of rebuilding and redefining self identity.

4.3. Social orientation

4.3.1. Disconnection and isolation

A shared phenomenon of feeling isolated and disconnected from others emerged. Pat summed this up saying: 'The sound of silence. There is a lot of silence' (10.232). For some, isolation and disconnection was an experience enforced on them because of others: 'We have lost some friends to be honest, well people who I thought were [friends]. I don't know, maybe they can't handle it' (Malcolm. 4.106). However, others initially sought such isolation by disengaging from social activities and prioritising solitary activities:

> I stopped walking round the fields now with people I used to walk with because they are all self righteous. They all know better than the other one. I am not one of them sort of people. (George. 8.240)

> I just avoid people I don't like who are being negative towards me. (Emma. 17.521)

In some cases, people's experience of services heightened their sense of isolation. Participants spoke of their surprise at the lack of services for 'younger

people'. Don felt particularly let down and neglected by services: 'I think people with this complaint, it seems to me like they say "We have just put them over in that basket over there and just leave them on their own"' (12.275).

4.3.2. Reconnecting

Reconnecting is a theme that captures a process of re-engaging in life following people's initial experience of disconnection and isolation and represents another stage of adjusting to AD. Although disconnection was identified as a way of managing the sense of difference to others it was recognised that this could not be sustained long term. George implied the importance of reconnecting and continuing with life when he metaphorically discussed his walks in the wood: 'when I go in the woods I have got to make sure that I come back out…' (19.560).

Some participants' narratives of re-engaging took a determined stance of refusing to disconnect or hide away any longer. For example, Emma said: 'I am never going to be the quiet one in the corner! LAUGH' (27.822) and Don commented: 'I'm just going to give it my best shot, you know. I am not going to go and lock myself in' (19.451). For others re-engaging was about redeveloping a purpose in life:

> Well you have got to make something of your life. If you don't you are just like cabbage and I don't want to become a cabbage I want to be doing something. (Peter. 25.608)

> [having an allotment] gives us something to do, somewhere to go. It keeps everybody from under my feet. LAUGH. (John. 11.252)

It seemed that as people began to reconnect with others their focus shifted from concern with how they were going to cope to concern with how their loved ones cope: 'My wife. She's had so much to deal with. I just want to protect her and make sure she's alright (*participant tearful*)' (George. 35.1081)

Others focused their attentions on contributing to the community and helping other people with dementia: '…if I could help somebody else then I will do it because that will make me feel like I have had some part of things. I've always been a carer so I might as well keep doing it. LAUGH' (Emma. 16.482)

It is possible that the process of reconnecting is linked to the previous theme of redefining self as identity was strongly associated with society's responses to the disease. For example, as Don began to identify with and accept his diagnosis he felt more able to discuss it with others and the positive responses of others encouraged him to begin to re-engage in life.

4.4. Agency

4.4.1. Powerlessness and loss of agency

A common phenomenon for many participants was a sense of powerlessness and loss of agency – a sense that they are no longer in control of their own minds, actions, future and overall experience of living with AD:

> Oh I tell you, in your own mind you I know I hide stuff, I don't know why I do it, yet I do it and I know all the time that I am doing it.'
> (John. 18.462)

The early-onset of AD was so unexpected for most participants that it was experienced as an attack against which they had no defence: 'It has just taken over my life…' (Don. 2.26). However this sense of powerlessness persisted

beyond the time of onset and formed a major theme of their experience of living with AD. Many spoke of feeling a lack of control over the course of the disease: 'There is nothing I can do about it and that hurts a lot' (Pat. 7.156). For some, this powerlessness persisted despite the availability of medication designed to slow cognitive decline, resulting in people waiting passively for someone to find a cure: 'Basically there is nothing I can do about it is there unless someone comes up with a miracle cure for it.' (Pat. 23.554)

Another narrative of feeling powerless emerged in the way that participants referred to their experience of AD being likened to punishment. Using language that is usually associated with the law may reflect their experience of being restricted and controlled by the disease:

> I keep asking my wife "why is this happening?" It should be people in jail that should be getting this, not people out here, not people like us. (George. 17.500)

> I have always gone out but you can't go out on your own can you LAUGH so you know I feel like I am in prison. (Emma. 11.319)

Although most participants contributed to the overall theme of powerlessness and loss of agency, the impact of this experience divided the sample. For John, Emma, Peter, Don and Pat their experience of being powerless was entirely negative. For example, Pat commented: 'If it can go wrong, it will go wrong…Big style' (10.233). However, for John and George the feeling of having no control over the disease appeared to be a catalyst for acceptance:

> I don't bother about the future, let that come to me. (George. 27.829)

> You have to play the cards that you have been dealt, end of story. (John. 19.447)

The most consistent experience of loss of agency was over the future. Again, despite the availability of medication people felt unable to influence their future health: 'I know it is going to happen, I know I am going to get worse. I can't get better and I can't do anything to, to…I don't know.' (Peter. 23.546). Malcolm appeared to stand in contradiction to others; he referred to taking control of decisions now and putting plans in place such as making advanced directives. Although this does not prevent what Peter referred to as 'the inevitable [decline and death]' it enabled him to maintain some sense of self-agency.

4.4.2. Regaining control

The intention to regain control emerged as a common coping strategy in response to the experience of loss of agency:

> Coping is important because if you are coping you feel that you are a bit on top of it rather than it being on top of you. You feel that you have got some control over it in a way rather than being led along by it. Learning to cope with it is sort of putting it in its place rather than it just taking over. (Malcolm. 29.967)

> You know it is like someone saying to you "well, you will die in another month". You do what you want but in a month's time you will be gone so all you can do is take bull by the horns and live with it until you're gone. (John. 18. 427)

For Mark, regaining control was about regaining a sense of agency over decisions and how to cope with the disease: '…I am the one that is going to carry on and deal with the rest of my life in the best way I possibly can.' (Mark. 1. 27)

One way of taking control was through developing a narrative of getting tough. George argued: 'If it gets tough, I get tougher than that' (21.634). For some, this fighting talk conveyed a determination to carry on and not let the disease get the better of them: 'Yes, you can't just give in. Never give in, keep going.' (George. 30.924). Emma on the other hand developed a type of motivational speech but this seemed less persuasive, reflecting an uncertainty about its effectiveness as a coping strategy for her: 'I have just had to tell myself that I have got to get better and I have got to get on with it and everyday just keep smiling.' (Emma. 24.718)

5. Discussion

This was a qualitative study exploring the experience of living with and adjusting to AD in people under the age of 65 years. A central theme depicting a 'disruption of the life-cycle' emerged from the analysis and influenced both people's experience of and adjustment to having the condition. This suggests that the age of onset is a crucial factor in how people experience and respond to AD.

According to the findings, participants felt too young to develop a serious illness and especially AD that they associated with old age. This view and the early loss of adult competency left participants with a sense of premature aging and reduced life expectancy. Whilst the concept of being too young appeared intrinsic to the person with AD it was in part co-constructed by the responses of others. In fact, other people had a marked influence across individuals' entire experience of AD. A possible explanation may be that, according to

psychological models of human development, people of 'middle-age' are more socially situated compared to younger or older adults (Erikson, 1963).

The sub-theme of aging emerged as a socially constructed concept conveyed through language and interactions with others. This supports the social theory of aging whereby age is defined by people's ability to contribute to and fulfil certain social roles (Howard, 2000). Like in other chronic conditions the meaning of aging could be viewed as a positive or negative experience (Rozario & DeRienzis, 2009) and can serve to maintain a sense of youthful self or to explain biological decline. This may go some way to explain the individual conceptualisations of age identity across the sample, with most participants viewing themselves as 'too young' with one or two exceptions using aging as a way of understanding their condition and normalising the disruption to the life-cycle.

5.1. The lived experience

AD was experienced as a threat to self, a trigger to feeling disconnected to others and a loss of personal agency. The impact on self view was marked with participants reporting fundamental changes that threatened their sense of self and self-esteem. Similarly, Bury (1982) proposed that the onset of illness presents a 'biographical disruption' in which previously held self concepts and expected life course are challenged. However, the concept that chronic or terminal illness inevitably causes a loss of self is being challenged (e.g. Kontos, 2004). These findings suggest that loss of identity and self-worth was significantly influenced by the negative or stigmatised responses of others,

which reflect the social constructionist (e.g. Sabat, 2001) and social biographical theories (Surr, 2006) of self in dementia. The findings from this study also propose the importance of considering identity with a developmental context, which has not been considered in previous research. According to developmental theories identity during 'middle age' is socially situated and largely defined by the achievement of mastery and the sharing of skills and expertise with the wider society (Erikson, 1963). Thus, the threat of developing young-onset AD on self identity can be understood by the limitations it puts on the fulfilment of expected mid-life roles and the social stigma anticipated in response to this.

Disconnection also emerged as an important theme in the experience of living with young-onset AD. Interactions with and the responses of others left individuals feeling different creating a sense of isolation. Some actively sought ways to disconnect from others as their experience of difference grew. Radley (1994) suggests isolation may be a response to living with illness in a world of health. This was consistent with the discomfort of being 'ill' expressed by some participants. Awareness that a position of disconnection could not be sustained with continued decline created a sense of powerlessness, which mirrors findings on the experience of chronic conditions such as diabetes in younger people (i.e. Schur, Gamsu & Barley, 1999).

5.2. Adjusting to young-onset AD
Adjusting to and coping with AD in younger life emerged as a cyclical process of re-stabilising self, reconnecting with others, regaining control and further

reviewing life and life expectations. The strategies employed appeared to represent an attempt to move away from the experiences outlined above. Thus, the experience of living with AD and the strategies employed to cope with these appear to lie on a continuum. A number of coping theories suggest that a core aspect of coping is related to redressing balance in response to an event or experience (Lazarus & Folkman,1984). The dichotomy here may reflect an attempt to redress the balance in life.

Attempts to regain a stable identity were either aimed at preserving current self concept and compensating for losses or cutting off and re-defining self identity by incorporating their diagnosis. The initial desire to preserve their self concept could be explained as an early grief reaction, which has been linked with the defence of denial (Kübler-Ross, 1970) – in this case denial of change or denial of the extent of impact. The transition towards redefining self may represent the later stage of acceptance in grieving. This would support the suggestion that holding on is an early response to AD and a relatively short-term approach to adjustment. An alternative understanding can be drawn from the chronic health literature highlighting the importance of the body in the perception of the self during illness (Kelly & Field, 1996). At the early stage when signs of AD may be more 'hidden' attempting to preserve and portray a continued sense of self may be preferred. However, as people decline and the disease becomes more visible concealment may become impossible prompting the re-defining of self.

This dichotomy has been repeated in other dementia research (e.g. Clare, 2002; Pearce et al., 2002). It is difficult to conclude to what extent this is a unique

feature of coping in people with young-onset AD as previous samples have included a mix of ages including individuals under the age of 65 years. However, the findings highlight the importance of situating coping in a life-cycle frame, suggesting that coping and adjustment may be conceptually different in people with young-onset AD. Of course, it is possible that some experiences and aspects of coping with AD are significantly different for younger people (under 65 years) whilst other experiences share more commonalities. Further research is required before firm conclusions can be made.

Seeking to reconnect with others was a strategy that emerged in response to the experience of isolation. Although disconnection formed a coping response for some, there was a sense that reconnecting was a long-term aim. This may be due to awareness of the progression of the disease and the likelihood of needing to rely on others for care. Alternatively, this could be viewed as conceptually linked with the life-stage of the sample as middle-adulthood is strongly situated in a social context (Erikson, 1963). Thus, the importance of reconnecting may reflect a desire to achieve a level of age-related normality where the sense of connection and belonging to others is an essential part of mid-life development. This may also explain the strategy of regaining control. The literature suggests that people of mid-age are masters of their lives – the drivers rather than the driven (Lachman, 2004). AD threatens their ability to perform this age-normed role but taking control could be a way of attempting to redress this. The use of control in coping is supported in the literature on chronic pain (Bates & Rankin-

Hill, 1994), breast cancer (Taylor, 1983), asthma (Adams, Phil & Jones, 1997) and diabetes (Kelleher, 1988) in adulthood.

5.3. Methodological critique

The findings of this study must be viewed in light of its methodological limitations. First it is important to note that despite attempts to recruit more females through purposive sampling, the sample was predominantly male. Emotional difficulties regarding dementia diagnosis and other life events were the reasons given by people not wanting to participate in the study. Thus, it could also be assumed that the sample consisted of individuals that coped most effectively. Difficulties recruiting females may be suggestive of gender differences in coping with AD, which has been tentatively suggested in other research (Van Dijkhuizen et al., 2006; Pearce et al., 2002). However, no apparent differences emerged in the main findings of this study. Further research into potential gender differences could have important theoretical and clinical implications regarding the design of future studies and implementation of interventions. Another potential limitation regarding the sample was that despite attempts to protect homogeneity, age and time since diagnosis were somewhat variable. Previous research has reported similar issues and describes sample heterogeneity as an expected feature when recruiting people with early-stage dementia (Clare, Roth & Pratt, 2005).

A limitation of the design of this research is that participants' experiences of living and coping with AD were explored at one point in time; as such the study suffers the limitations associated with research employing a cross-sectional

design. Interviewing participants once meant that triangulation of data was not possible. Although triangulation was achieved in the analysis through the independent coding of three transcripts by two analysts, multiple interviews with participants may have been an additional way of demonstrating rigour in the study and may have highlighted changes in adjustment over time. Future research may benefit from adopting a longitudinal design with multiple interviews per participant.

Finally, it is acknowledged that having a carer present during interview may have a detrimental effect on data collection. One participant spoke of needing to protect his family; although he was able to speak about his difference of opinion compared to other family members thought was given to the possibility of him with-holding some details. This difficulty has to be carefully balanced with the benefits that third parties may have on participants' sense of support. Thus, a decision was made to discuss this issue with participants when booking in further interviews. Although participants still had the choice of having a carer present they typically only stayed for the initial introductions until a rapport was developed between researcher and participant.

5.4. Theoretical and clinical implications

Despite some limitations the study makes a valuable contribution to the theoretical understanding of dementia and the clinical foundations of dementia care. The findings demonstrate that the experience of living with young-onset AD is strongly situated in a conceptual framework of personhood in which the very core of people's identity is rocked by the decline in age-related abilities.

However, identity was strongly situated in a social frame, which reflects the mid-life stage of human development (i.e. Erikson, 1963). Therefore this research argues that personhood in middle adulthood is a fluid concept that has to be considered within a life-cycle or human development frame. As such, the experience of living with AD is emerging as a unique experience for people of working age. Although, similar coping and adjustment processes have been found in studies with older adults, samples have often also included those with young-onset dementia. This makes it difficult to determine what is unique to young-onset dementia and what commonalities are shared with those developing the disease later in life. The predominance of feeling too young for AD in this sample suggests that coping is, at least in part, conceptually different for people with young-onset AD. As such, these findings appear to sit most appropriately with the chronic illness models relating to younger people (i.e. Aldwin & Brustrom, 1997; Charmaz, 1983).

These findings have significant implications for further research. Further studies investigating the experiences of individuals with young-onset dementia should be carried out to clarify age effects. In particular, research into the experience of younger people with non-Alzheimer's dementia would be useful as these may have different physical, behavioural and cognitive effects and may to some extent be less strongly associated with old age. The study has demonstrated the value of making young people with dementia the focus of research. Research aimed at developing clinically relevant models of coping would be particularly beneficial to advance on this paper.

Further to the dementia literature, this research lends support to life-cycle models of human development. In particular it offers additional understanding to the mid-life evidence-base which has long been recognised as another under researched area (Lachman, 2004). The findings also draw close parallels to the chronic and terminal illness literature. Thus, it may be important for further research in these areas to focus on the effects and experiences of illness onset during mid-life.

The findings also have important implications for clinical practice and service development. Participants reported feeling an increased sense of difference and isolation as a result of the lack of service provision for younger people. These findings suggest a need to develop specialist services for younger people with dementia. Group-based interventions may be particularly useful as they have been found to increase self-worth and may counteract the challenges to self and increase quality of life (Clare, Rowlands & Quin, 2008). Group work may be particularly effective for people with young-onset dementia given that middle-age is strongly situated in a social framework (Erikson, 1963). Self help groups may provide a channel through which young people with AD can continue to contribute to wider society helping to fulfil expected age-related tasks. It may also facilitate individuals' natural attempts to cope with the disease through allowing them to take control and regain a sense of agency. Furthermore these have been found to be of greater benefit than facilitator led groups and there is emerging literature to show the useful application of these in dementia care (Clare et al., 2008).

The study highlighted the significance of others and the impact of stigma on their experience of AD. Thus, it seems that there is great need for increased health promotion relating to young-onset dementia. Participants spoke of the usefulness of celebrities such as Sir Terry Prachett sharing their experience of young-onset AD; these findings argue that more work needs to be done at a societal level to challenge the inaccurate views of dementia and particularly dementia in younger people.

6. Conclusion

This study provides a preliminary exploration of the experience of living with and adjusting to young-onset AD. It supports the importance of seeking and prioritising the experiences of people with dementia. Age of onset was found to have an important impact on people's experience of and response to AD. The condition disrupted people's typical progression through the life-cycle and compromised their ability to fulfil age-related roles. This raised difficulties relating to an unstable sense of self, social isolation and loss of agency. Adjustment to these experiences emerged as a cyclical process of re-stabilising self, reconnecting with others, regaining control and reviewing life. These strategies lay at the opposite end of a continuum to the lived experiences and appeared to be an attempt to redress and normalise the life-cycle by developing competency over typical mid-life tasks (i.e. Erikson, 1963). The research makes an important theoretical contribution in that it supports the conceptual approach of personhood in dementia research and practice but suggests that this must be set within a life-cycle frame to remain meaningful for younger people.

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8. Appendices

Appendix A. Journal Approval Letter and Contributor's notes for

Dementia: International Journal of Social Research and Practice.

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Dementia
The International Journal of Social Research and Practice

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Manuscript Submission Guidelines:

Notes for Contributors

1. The aim of the journal is to publish original research or original contributions to the existing literature on social research and dementia. When submitting papers for consideration, please attach a letter confirming that all authors have agreed to the submission, and that the article is not currently being considered for publication by any other paper or electronic journal.

2. Each paper submitted, if considered suitable by the Editors, will be refereed by at least two anonymous referees, and the Editors may recommend revision and re-submission.

3. *Length of papers.* Brief articles should be up to 3000 words and more substantial articles between 5000 and 8000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length. Please also supply an abstract of 100-150 words, and up to five keywords arranged in alphabetical order.

4. When submitting a paper for consideration, our preferred method of receipt is as an electronic version and as a Microsoft Word document. This should be sent via email attachment to one of the Editors outlined in Note 18, together with a separate covering letter. If this is not practicable, please supply one paper copy and the article on a PC-compatible disk (containing text and all illustrations). Rejected papers will not be returned to authors.

5. Your typescript (written in English) needs to be typed using double spacing on one side only of white A or US standard size paper, with generous left and right-hand margins (at least .cms) but without justification.

6. Your title page should give: one first name as well as the surname and any initials for each author; a maximum of four degrees/qualifications for each author and the current relevant appointment only; authors' accurate postal addresses; daytime telephone numbers, and fax and email numbers.

7. *Quotations.* Lengthy quotations (over 40 words) should be displayed and indented in the text.

8. American or UK spellings may be used. Please use single quotation marks. Dates should be in the form '9 May 2000'. Delete full stops/periods from 'USA' and other such abbreviations.

9. If the paper is accepted for publication, a copy of the final version will be required as either an email attached Microsoft Word document, or on disk in a PC-compatible format. The author is responsible for ensuring that the final version of the article matches exactly the one required by the Editors.

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Downs, M. (1997). The emergence of the person in dementia research. *Ageing and Society*, 17(4), 597-607.

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

Morse, J. M. (1994). Emerging from the data: The cognitive processes of analysis in qualitative inquiry. In J. M. Morse (Ed.),

Critical issues in qualitative research methods (pp. 23-43). London: Sage.

Multi-authored articles: in the text, when the work has two authors, always cite both names every time. When there are more than two authors and less than six, cite all authors the first time and after that, just the surname of the first author and et al. The names of all authors should be given in the reference list.

14. *Language and terminology*. Jargon or unnecessary technical language should be avoided, as should the use of abbreviations (such as coded names for conditions). Please avoid the use of nouns as verbs (e.g. to access), and the use of adjectives as nouns (e.g. dements). Language that might be deemed sexist or racist should not be used.

15. *Abbreviations*. As far as possible, please avoid the use of initials, except for terms in common use. Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviations in brackets) the first time they are mentioned in the text.

16. The corresponding author will receive page proofs for checking. Twenty-five free offprints will be sent to the corresponding author, and each of the co-authors will receive a free copy of the journal.

18. *Typescripts*. Authors should retain a copy of their typescript and send an identical electronic version as a Microsoft Word document, together with all figures and tables and a separate covering letter, via email attachment to:

For USA and Canadian contributors:

Phyllis Braudy Harris

Editor, Dementia:

The International Journal of Social Research and Practice,

Department of Sociology,

John Carroll University,

North Park Boulevard,

University Heights,

Cleveland, Ohio, USA.

[email: pharris@jcu.edu]

For UK/Europe and the rest of the world:

John Keady

Professor of Mental Health Nursing and Older People,

School of Nursing, Midwifery & Social Work,

University of Manchester,

University Place (Room 6.321),

Oxford Road,

Manchester,

M13 9PL, UK

[email: john.keady@manchester.ac.uk]

Alternatively, authors should retain one copy of their typescript and supply one paper copy and the article on a PC-compatible disk (containing text and all illustrations) and a separate covering letter, to one of the Editors named above.

19. *Reviews*. Books for review should be sent to:

Book Review Editor - Dementia

Heather Wilkinson

College of Humanities & Social Science,

Univeristy of Edinburgh,

55-56 George Square,

Edinburgh

EH8 9JU, UK.

[email: hwilkins@staffmail.ed.ac.uk]

20. *Innovative Practice*. The Journal also welcomes submitted papers on various aspects of innovative practice in dementia care. Submissions for this part of the journal can be between 750-1500 words and should follow the criteria set out above. Correspondence should be sent to:

Jo Moriarty,

c/o School Offices,

School of Social Science and Public Policy,

Strand Building,

King's College London,

London, UK.

[email: jo.moriarty@kcl.ac.uk]

English Language Editing Services: Please click here for information on professional English language editing services recommended by SAGE.

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Appendix B. Part Example of the Mini Mental State Examination (Folstein,

Folstein, & McHugh, 1975).

Edited due to copyright

Appendix C. Clinician's Standardised Script for Introducing the Research.

A Trainee Clinical Psychologist at Sheffield University is carrying out a piece of research for her Doctorate Thesis exploring people's experience of living with and adjusting to having Alzheimer's Disease (AD) in younger life. Our service is one of four services that have agreed to help her recruit participants for the research by asking all of those that are suitable for the research whether they would like to be involved.

The reason I am talking to you about it is because she is looking for people under the age of 65 years who have a diagnosis of AD who would be able (and willing) to talk to her about their experiences. She is particularly interested in understanding what it is like for you to have AD, how it has impacted on you both psychologically and socially and most importantly how you cope with having the disease.

If you chose to participate in the study you would be asked to talk with the researcher about your experiences for around one hour, although this can be split into two shorter sessions if that would feel more comfortable. The researcher would also like to administer the Mini Mental State Examination with you too. You can chose whether to be interviewed at home or at a clinic base and you are welcome to have a carer, family member or friend present although the researcher is interested in your views so your carer would not be asked to contribute to the interview directly (e.g. answering for you). The interviews will be tape-recorded so they can be transcribed.

Full details of the study are provided on this information sheet, which I would encourage you to read prior to deciding whether you would like to be involved or not. If you are interested in participating or knowing more about the research please can you complete the 'consent to be contacted form' and the researcher will contact you directly. And answer any queries or make arrangements to continue with the study.

Appendix D. Initial Contact Letter.

Name of Service
Address
Telephone

Date

Client's address

RE: 'Adjusting to Alzheimer's disease in younger life' research project

Dear [name]

This is a letter inviting you to participate in a research project that is being supported by the Memory Clinic. The research is being conducted by a Trainee Clinical Psychologist at the University of Sheffield.

The research aims to explore people's experiences of living with dementia in younger life – under 65 years. More specifically it is interested in gaining an understanding of how people naturally attempt to adjust to and cope with the condition. The hope is that this information could help inform services about how they can best support people in this process.

The researcher would like to offer anybody under the age of 65 years with a medical diagnosis of Alzheimer's Disease who is in the mild to moderate stages the chance to be involved in the research.

An information sheet giving more details of the research is enclosed for anybody who would like to be involved.

If you would like to participate in the research please complete the enclosed form tilted "consent to be contacted" and return it in the freepost envelope provided. The researcher will then contact you by telephone to talk more about participating in the study.

If you have any further queries please leave a message for the researcher, Gemma Clemerson, at the university on (0114) 2226650 and she will return your call.

Yours sincerely

Memory Clinic Manager

Experiencing and adjusting to Alzheimer's Disease in younger life.

We would like to invite you to take part in a research study. Before you decide it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and to discuss it with others if you wish. Ask if anything is unclear or if you would like more information. Please feel free to take time to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of the research? To explore people's experience of living with Alzheimer's Disease (AD) in younger life (under 65 years) and to learn how people naturally attempt to adjust to and cope with the condition.

Why have I been invited? We are inviting individuals under the age of 65 years who have a diagnosis of AD and who access Memory Clinics or Dementia Services in the Chesterfield, Doncaster, Rotherham and Sheffield areas. We are hoping to recruit 10-12 people who could be interviewed about their experiences of coping with the disease.

Do I have to take part? It is your choice whether or not to take part. If you do decide to take part you will be given this information sheet to keep and you will be asked to sign a consent form to show you have agreed to take part. You can withdraw at any time without giving a reason and any data you have given us can be destroyed if you wish. This would not affect the services you receive.

What will I have to do? If you agree to take part you will be asked to speak to the researcher about your experience of living with and adjusting to AD, for example whether it has influenced the things you do, the people you see or the way in which you think or feel. The conversation will be tape-recorded and transcribed. It is anticipated that this will take approximately 1 hour which can be split into two shorter slots if preferred.

The researcher can meet with you at your home address or at a hospital base where you may have other appointments. You are welcome to have a family member, friend or carer present with you throughout the time spent with the researcher, however, we would ask for them not to contribute to the discussions directly. It is anticipated that you will be requested to meet with the researcher between November 2009 – February 2010.

Prior to the interview the researcher will go through this sheet with you and ask you to sign a consent form to say you agree to participate. You will also be asked to complete a Mini Mental State Examination (MMSE), which will be used to describe the sample of participants studied. Following data analysis, some participants may be asked to comment on the researcher's findings but again this will be entirely voluntary.

What will happen to the results? All participants will be offered a copy of the results. The results will form part of the final report, which will be submitted for publishing.

What are the possible disadvantages or risks of taking part? You may find talking about your experiences upsetting. You can choose whether or not to discuss certain aspects of your experiences and you can stop the interview at any time. If you do feel upset you can speak to the researcher at the time of the interview or you can contact your

usual dementia clinician, your GP or Claire Isaac (Research Supervisor – see contact below).

What are the possible benefits of taking part? Some people find talking about their experiences very helpful. We can not promise that this research will help you directly however it may help raise awareness and understanding of AD in younger people and may influence service development.

Who is organising, funding and insuring the research? The research is being undertaken as a thesis for an educational qualification (Doctorate) in Clinical Psychology. It is funded and insured by the University of Sheffield.

What if I want to complain about the study? If you have a concern about any aspect of this study you can ask to speak to the researcher who will do their best to answer your questions. Alternatively you can contact the research supervisors (see contacts below).

If you remain unhappy and wish to complain formally, you can do this through the NHS complaints Procedure, which can be obtained from your local hospital. Alternatively, you can follow the University complaints procedure by contacting: Dr David Fletcher, Registrar and Secretary's Office, University of Sheffield, Firth Court, Western Bank, Sheffield S10 2TN.

Will the information I give be kept confidential? Yes, all information collected will remain strictly confidential; the information you give will be anonymised (name/ address removed) meaning you will not be identified in any reports or publications. A professional transcriber will be used to transcribe the audio tapes and all tapes will be destroyed following data analysis; prior to this they will be kept in a lock cupboard. The transcripts may be looked at by authorised persons from the university and regulatory authorities who may wish to check that the study is being carried out correctly. All persons will have a duty of confidentiality to you as a participant and we will do our best to meet this duty.

The only exception to confidentiality is if you tell me something that indicates that you or someone else is at risk; I would be obliged to inform a professional involved in your care of this. However, I would endeavour to discuss this with you first.

Who has ethically reviewed the project? The study has been granted NHS ethical approval by 'Nottingham 1 Research Ethics Committee'. This means a group of NHS employees and lay volunteers have agreed that the research has the necessary procedures and safeguards to protect the rights, safety, dignity and well-being of all participants.

Contact for further information regarding the study and any concerns/ complaints.

Researcher: Gemma Clemerson, Trainee Clinical Psychologist, University of Sheffield, Western Bank, Sheffield, S10 2HP. If you wish to speak to the researcher please leave a message with the research support officer on (0114) 2226650 and the researcher will call you back. Supervisors: Dr. Claire Isaac, Lecturer and Practitioner, University of Sheffield, Western Bank, Sheffield, S10 2HP. Tel: (0114) 2226639. Dr. Sue Walsh, Clinical Tutor Lead, University of Sheffield, Western Bank, Sheffield, S10 2HP. Tel: (0114) 2226567.

Participant Consent Form

Title of Project: Experiencing and adjusting to dementia in younger life.

Name of Researcher: Gemma Clemerson

Participant Identification Number for this project: **Please initial box**

I confirm that I have read and understand the information letter dated……… for the above project and have had the opportunity to ask questions and had these answered satisfactorily.

I understand that my participation is voluntary and I am free to withdraw at any time without giving a reason, without my medical or legal rights being affected. Please leave a message for the researcher on (0114) 2226650 if you wish to do this and she will return your call.

I understand that data collected during the study may be looked at by authorised individuals from the University, regulatory authorities or the NHS Trust for monitoring purposes. I give permission for these individuals to access this data.

I agree to my responses being quoted in the research paper including if the paper is published

I agree to the interview being tape recorded

I agree to take part in the above research project.

I agree to the researcher accessing my notes if necessary

If I lose capacity to consent during the study I agree to the data I have already given being included in the final report

---

_____   _____   _____
Name of Participant   Date   Signature
(*or legal representative*)

_____   _____   _____
 Lead Researcher   Date   Signature
To be signed and dated in presence of the participant

Copies: *Once signed by all parties the participant should receive a copy of the signed and dated consent form, the information sheet and any other written information provided to the participants. A copy for the signed and dated consent form should be placed in the project's main record (e.g. a site file), which must be kept in a secure location.*

Appendix G. Consent to be Contacted Form

Consent to be contacted regarding the research:

Experiencing and living with dementia in younger life: an interpretative phenomenological analysis.

If you wish to volunteer to participate in this research or if you wish to know more about the study please complete the following details:

Name:

Age:

Home address:

Telephone number:

Mobile number:

I agree to be contacted by the researcher, Gemma Clemerson, to discuss the study and my potential involvement further.

Signature:

Appendix H. Ethical Approval Letter.

Nottingham Research Ethics Committee 1

1 Standard Court
Park Row
Nottingham
NG1 6GN

Telephone: 0115 8839390 (Direct Line)
Facsimile: 0115 9123300

05 November 2009

Mrs Gemma Clemerson
25 Jenny Becketts Lane
Mansfield
Notts
NG18 4HP

Dear Mrs Clemerson

Study Title: **Experiencing and adjusting to Alzheimer's Disease in younger life: an interpretative phenomenological analysis**
REC reference no: **09/H0403/66**
Protocol number:

Thank you for your letter of 26 October 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.

Ethical review of research sites

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

Conditions of the favourable opinion

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

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

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on

applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk. *Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.*

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

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
Letter from Sponsor		22 May 2009
Covering Letter		
Protocol	1	13 July 2009
REC application	20179/49971/1/826	13 July 2009
Advertisement	1	13 July 2009
Interview Schedules/Topic Guides	1	13 July 2009
Peer Review	X 2	21 April 2009
Investigator CV	Student	13 July 2009
Investigator CV	Academic Supervisor	13 July 2009
Participant Information Sheet	2	26 October 2009
Participant Consent Form	2	26 October 2009
Letter of invitation to participant	2	26 October 2009
Consent to be contacted form	2	26 October 2009
Response to Request for Further Information		26 October 2009
Letter of support from Lead Clinician for Early Onset Dementia Services in Rotherham		04 September 2009
Letter of support from Lead Clinician for Early Onset Dementia Services in Doncaster		01 October 2009
Lead Clinician for Young Onset Dementia Services at Rotherham, Doncaster and South Humber Mental Health NHS Foundation Trust		01 October 2009
Letter of support from Lead Clinician (Team Manager) for Young Onset Dementia Services at Rotherham, Doncaster and South Humber Mental Health NHS Foundation Trust		01 October 2009
Email trail from Lead Clinicians at the Neurology Memory Clinic at the Hallamshire Hospital, Sheffield		05 October 2009
Email trail from Lead Clinician at the Chesterfield Memory Service		21 October 2009

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/H0403/66	**Please quote this number on all correspondence**

Yours sincerely

Dr Kate Pointon
Chair

Email: trish.wheat@nottspct.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: *University of Sheffield*

               R&D office for NHS care organisation at lead site – RDASH NHS Trust

Appendix I. Scientific Approval Letter.

The
University
Of
Sheffield.

Department Of Psychology.
Clinical Psychology Unit.

Doctor of Clinical Psychology (DClin Psy) Programme
Clinical supervision training and NHS research training
& consultancy.

Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield S10 2TP UK

Telephone: 0114 2226570
Fax: 0114 2226610
Email: dclinpsy@sheffield.ac.uk
Please address any correspondence to Ms. Christie
Harrison, Research Support Officer

21st April 2009

Research Governance Office

Dear Sir/Madam,

RE: Confirmation of Scientific Approval of enclosed Research Project

Project title: Experiencing and adjusting to Alzheimer's Disease in younger life: an interpretative
phenomenological analysis
Investigators: Gemma Clemerson (DClin Psy Trainee, University of Sheffield); Dr Claire Isaac; Dr
Sue Walsh (Academic Supervisors, University of Sheffield).

I write to confirm that the enclosed proposal forms part of the educational requirements for the
Doctoral Clinical Psychology Qualification (DClin Psy) run by the Clinical Psychology Unit, University
of Sheffield.

Three independent reviewers appointed by the Clinical Psychology Unit Research Sub-committee
have scientifically reviewed it.

I can confirm that all necessary amendments have been made to the satisfaction of the reviewers,
who are now happy that the proposed study is of sound scientific quality.

*Given the above, I would ask that you consider this proposal for exemption from any further NHS
scientific review.* The Unit already has an agreement with several local NHS Trusts (SHSRC, STH &
SCH) to this effect. If you require any further information, please do not hesitate to contact me.

Yours sincerely

Dr. Andrew Thompson
Director of Research Training

Cc. Gemma Clemerson, Dr Claire Isaac, Dr Sue Walsh

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The
University
Of
Sheffield.

Research &
Innovation
Services.

A Section of Academic Services

Mrs Gemma Clemerson
C/O Christie Harrison
Clinical Psychology Unit

New Spring House
231 Glossop Road
Sheffield
S10 2GW

16 November 2009

Telephone: +44 (0) 114 222 1400
Fax: +44 (0) 114 222 1452
Email: l.smaller@sheffield.ac.uk

Project title: Experiencing and adjusting to Alzheimer's Disease in younger life: an interpretative
phenomenological analysis
6 digit URMS number: 125486

Dear Gemma

**LETTER TO CONFIRM THAT THE UNIVERSITY OF SHEFFIELD IS THE PROJECT'S
RESEARCH GOVERNANCE SPONSOR**

Research and Innovation Services has reviewed the following documents:

1. A University approved URMS costing record;
2. Signed, dated confirmation of scientific approval;
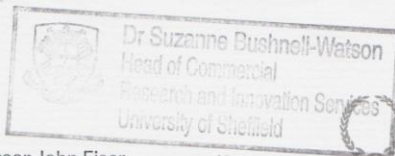3. Signed, dated confirmation of ethics approval.

All the above documents are in place. Therefore, the University now **confirms** that it is the project's
research governance sponsor and, as research governance sponsor, **authorises** the project to
commence research activities.

You are expected to deliver the research project in accordance with the University's policies and
procedures, which includes the University's Good Research Practice Standards:
www.shef.ac.uk/researchoffice/gov_ethics_grp. You are also expected to publish a lay summary of the
project on the website of the National Research Ethics Service (NRES), as it appears in the research
ethics application.

Your Supervisor, with your support and input, is responsible for monitoring the project on an ongoing
basis. Your Head of Department is responsible for independently monitoring the project as
appropriate. The project may be audited during or after its lifetime by the University. The monitoring
responsibilities are listed in **Annex 1**.

Yours sincerely

Dr Suzanne Bushnell-Watson
Head of Commercial
Research and Innovation Services
University of Sheffield

cc. Supervisor: Dr Claire Isaac
Head of Department/School: Professor John Eiser

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Appendix J. Governance Letter of Approval.

Rotherham Doncaster and **NHS**
South Humber Mental Health

NHS Foundation Trust

Clinical Effectiveness Department
Birch View, St Catherine's, Tickhill Road,
Balby, Doncaster. DN4 8QN
Telephone: 01302 796726
Fax: 01302 796729
E.mail : helen.oldknow@rdash.nhs.uk

HJO/CAE

12th November 2009

Mrs Gemma Clemerson
25 Jenny Becketts Lane
Mansfield
Notts
NG18 4HP

Title of project: **Experiencing and adjusting to Alzheimer's disease in younger life: an interpretative phenomenological analysis**

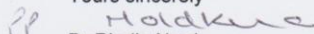REC reference number: 09/HO403/66

Dear Gemma Clemerson

Rotherham Doncaster & South Humber Mental Health NHS Foundation Trust has reviewed your above project for Organisational approval. We can confirm that the research project meets the requirements for Research Governance and we now give you Trust approval.

However if the protocol should change you would have to re-submit your new proposal. May we remind you that you are obliged to adhere to the Research Governance Framework for Health and Social Care.

In the interest of ensuring the Trust receives maximum benefit from co-operating with research projects such as your own, the Trust places great importance on disseminating findings and conclusions. Therefore we would welcome a short summary of the findings of this project, once completed, along with any formal publications resulting from this work.

May I take this opportunity to wish you well with your project. If you have any concerns please do not hesitate to contact Helen Oldknow on 01302 796762.

Yours sincerely

pp   Holdknow

Dr Riadh Abed
Medical Director

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Christine Boswell - Chief Executive   Madeleine Keyworth - Chairman

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NHS Foundation Trust
HR Dept
St Catherine's, Tickhill Road,
Balby, Doncaster. DN4 8QN
Telephone: 01302 796726
Fax: 01302 796729
helen.oldknow@rdash.nhs.uk

13 November 2009

Ms Gemma Clemerson
Trainee Psychologist
Sheffield University
Weston Bank
Sheffield

Dear Ms Clemerson

Letter of access for research

This letter confirms your right of access to conduct research through Rotherham
Doncaster and South Humber Mental Health NHS Foundation Trust for the purpose and
on the terms and conditions set out below. This right of access commences on
16 November 2009 and ends on 31 December 2010 unless terminated earlier in
accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter
of permission for research from this NHS organisation. Please note that you cannot start
the research until the Principal Investigator for the research project has received a letter
from us giving permission to conduct the project.

The information supplied about your role in research at Rotherham Doncaster and South
Humber Mental Health NHS Foundation Trust has been reviewed and you do not require
an honorary research contract with this NHS organisation. We are satisfied that such pre-
engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to Rotherham Doncaster and South Humber
Mental Health NHS Foundation Trust premises. You are not entitled to any form of
payment or access to other benefits provided by this NHS organisation to employees and
this letter does not give rise to any other relationship between you and this NHS
organisation, in particular that of an employee.

While undertaking research through Rotherham Doncaster and South Humber Mental
Health NHS Foundation Trust, you will remain accountable to your employer Royal Free
but you are required to follow the reasonable instructions of Mrs Jan Smith, Assistant
Director Older Peoples' Mental Health Services in this NHS organisation or those given
on his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising
out of or in connection with your right of access, you are required to co-operate fully with
any investigation by this NHS organisation in connection with any such claim and to give
all such assistance as may reasonably be required regarding the conduct of any legal
proceedings.

You must act in accordance with Rotherham Doncaster and South Humber Mental Health
NHS Foundation Trust policies and procedures, which are available to you upon request,
and the Research Governance Framework.

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You are required to co-operate with Rotherham Doncaster and South Humber Mental Health NHS Foundation Trust in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on Rotherham Doncaster and South Humber Mental Health NHS Foundation Trust premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.
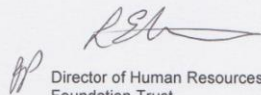
You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

Rotherham Doncaster and South Humber Mental Health NHS Foundation Trust will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely

Director of Human Resources, Rotherham Doncaster and South Humber Mental Health NHS Foundation Trust

cc: R&D office at Rotherham Doncaster and South Humber Mental Health NHS Foundation Trust
        HR department of the substantive employer

Appendix K. Transcriber Confidentiality Form and Guidelines for Transcribers.

Doctorate in Clinical Psychology, University of Sheffield

Transcriber Confidentiality Form

Type of project: Research thesis

Project title: Experiencing and adjusting to dementia in younger life: an interpretative phenomenological analysis.

Researcher's name: Gemma Clemerson

The tapes you are transcribing have been collected as part of a research project. Tapes may contain information of a very personal nature, which should be kept confidential and not disclosed to others. Maintaining this confidentiality is of utmost importance to the University.

We would like you to agree:

- Not to disclose any information to others that you hear on the tapes
- To keep the tapes in a secure locked place when not in use
- When using the tapes to ensure it cannot be heard by other people
- To adhere to the Guidelines for Transcribers in relation to the use of computers
- To show your transcription only to the relevant individual who is involved in the research project.

If you find that anyone speaking on a tape is known to you, we would like you to stop transcription work on that tape immediately and inform the person who has commissioned the work.

Declaration

I have read the above information, as well as the enclosed Guidelines for Transcribers and I understand that:

1. I will discuss the content of the tape only with the individual involved in the research project
2. I will keep the tape in a secure place where it cannot be heard by others
3. I will treat the transcription of the tape as confidential information
4. I will adhere to the requirements detailed in the Guidelines for transcribers in relation to transcribing tapes onto a computer
5. If the person being interviewed on the tapes is known to me I will undertake no further transcription work on the tape

I agree to act according to the above constraints

Your name _____

Signature _____

Date _____

Occasionally, the conversations on tapes can be distressing to hear. If you should find it upsetting, please stop the transcription and raise this with the researcher as soon as possible.

Researcher contact details:

Email: pcp07gh@sheffield.ac.uk

Mobile: 079********

<center>**Guidelines for transcribers**</center>

Introduction

The course has created the guidelines below for anyone who is involved in transcribing data for staff or trainees in the Clinical Psychology Unit, University of Sheffield.

In addition to adhering to the following guidelines, **transcribers must sign a confidentiality form** prior to beginning any work. If you are unsure about any of the information given below, or for a copy of the confidentiality form, please contact the relevant trainee.

Transcribing

When undertaking transcribing, you must:

- Password protect the computer files you are typing **before you type any text** – this can be done easily in Microsoft Word, as follows:

Instructions for a PC:

For Word 1998-2003

1) Open a blank Word document
2) Go to Tools on the menu bar and select Options
3) Go to the Security tab and insert a password to open the document. You will be asked to re-type this, then please ensure you click ok before closing the Options menu.

For Word 2007:

1) Open a blank Word document
2) Go to Save As and choose the compatible mode
3) Click Tools, then select General Options
4) Enter a password to open the document. You will asked to re-type this, then please ensure you click ok before closing the dialogue box.

Instructions for a Mac:

1) Open a blank Word document
2) Go to Word on the menu bar and select Preferences

3) Click on Security and insert a password to open the document. You will be asked to re-type this, then click ok.

- Anonymise any personal information contained in the data you are transcribing as you type e.g. names. Please contact trainee or member of staff who transcribing you are doing if you have any queries about this.
- Delete any files from your computer (including from your 'Trash' folder) once you have submitted your completed transcription.

Appendix L. Interview Introduction Script and Schedule.

Code: Black = initial schedule items
Orange = additional items following pilot interview
Green = revised or additional items previous interviews

Standard introduction

My name is Gemma Clemerson and I am training to become a Clinical Psychologist. I am conducting this research as part of my training. The aim of the research is to gain an understanding of people's individual experiences of living with dementia in younger life and how they attempt to adjust to and cope with the condition.

This is an information sheet for you to keep that tells you all about the study. I would like us to go through this together to make sure everything is clear before I ask you to sign a consent form to say that you understand what the study is about and that you agree to take part. Even if you sign this form now, you can still withdraw from the study or terminate the interview at any time.

[Go through information sheet and consent form] Is there anything that isn't clear or are there any questions you would like to ask before we begin?

To reiterate, the main aims of the study are to:

- find out a little more about you

- explore the impact that dementia has had on your everyday life

- explore the impact it may have had on your psychological well-being

- and mainly to gain an understanding of how you have adapted to and coped with any difficulties the condition has caused you.

These aims are written on this piece of card that you can use refer back to if you wish.

I have a few questions that I will ask you but really my aim is for you to be able to tell your story in your own words so hopefully you will do most of the talking from now on.

START THE TAPE RECORDER

1. **Can you start by telling me a little bit about your thoughts or views on dementia and potentially how these have changed since you've experienced it first hand?**

Possible areas to cover: Had you ever thought about dementia? Do you have particular associations with the disease?

2. **Can you tell me briefly about what life was like for you before you developed dementia?**

Possible areas to cover: Family life/ employment/ social activities

3. **Can you describe how having dementia impacts on your everyday life as a younger person?**

Possible areas to cover: work/ social/ general functioning/ impact on family

4. **Can you describe any effects it has had on your psychological wellbeing such as your mood, self-esteem or self-identity?**

5. How do you feel about having Alzheimer's disease at your age?

6. Can you describe to me how you have tried to manage and cope with the challenges that dementia has presented for you?

Additional prompts if required:

Have you stopped doing things or started doing new things to cope with changes you've experienced?

Have you found yourself thinking about things in a different way?

Has receiving drug treatment had an impact on your coping/ adjusting?

What factors influence the way you cope? (i.e. personality, knowledge, experience)

7. Have you always coped with difficult situations in this way or have you had to find new ways to cope since developing the condition?

8. What does it mean to you to be coping/ adjusting to Alzheimer's disease?

Additional prompts if required:

Specific examples of times when coped well or not and how this feels

9. Is there anything that services or other people could do to further help you cope with or adjust to the condition?

10. What are you thoughts regarding the future? What do you think the future holds for you?

<u>Standard ending</u>

We have reached the end of my questions now. Is there anything that you would like to add that you feel you have not had chance to cover? Given the aims of the research, which are written here (point to prompt) are there any questions that you were expecting me to ask that I didn't, or any further questions that you think would be useful to ask?

STOP THE TAPE RECORDER

Before we finish I would also like to ask some more specific questions about you so I can describe the people that took part in the study.

Age:

Gender:

Ethnicity:

Birth place:

Age when diagnosed:

Previous/ current employment:

Living arrangements:

Partner details: age, employment status

Appendix M. Prompt Card of the Aims of the Study to be Used in the Interview.

The main aims of the study are:

1. find out a little more about you

2. explore the impact that dementia has had on your everyday life

3. explore the impact it may have had on your psychological well-being

4. and mainly to gain an understanding of how you have adapted to and coped with any difficulties the condition has caused you.

Initial case-by-case ideographic analysis

Below is a five page section of Malcolm's transcript representing a worked

example of the initial case-by-case analysis/ coding process. The section of

transcript is annotated with initial phenomenological codes in the right hand

margin and interpretative codes in the left hand margin.

The following codes emerged for Malcolm:

Preserved self	Loss of agency
Change in self	Loss of skills
Clinging on to self	I am too young for AD
Taking control	Medication
Emotional impact	Acceptance
Aging	Adjusting
Loss self-esteem	Different point of view
Change in role	Social support
Feared stigma/ others view of me	Cause
Typical aging	Diagnosis/ knowing
Making sense and reconceptulaising	Loss of future expectations
Re-defining self	Social loss
I am too young to die	

Following the initial coding, the next stage of the case-by-case analysis

involved organising the above codes into coherent collections of similar themes.

This produced a set of super-ordinate and sub-themes that are presented in table

1.

408 why that is, there is no point worrying bout it so you just
409 carry on. You sort of broadly get the things but yes there is
410 probably quite a bit of detail of stories and things and things
411 that I had probably missed/forgotten but I have generally got
412 the idea of things as it has gone through.
413
414 **I:** So is it just adapting how you go about it?
415
416 **P:** Yes, yes I think it is yes. I can still do photographs, I like
417 doing that with my camera so I can go out and that is still
418 okay, I have don't that for years and years and years.
419
420 **I:** How important is it to hold on to the things you can do?
421
422 **P:** Oh, it is important because it is a link, it is the past. I
423 think a lot more about the past now, I suppose that is easier in
424 a way because things I forget are certainly the most recent
425 things erm and I know that is pat of it. Erm so perhaps the
426 past becomes more important that was as well because you
427 want to cling on to who you are so things in the past are very
428 important and perhaps seem more important than they did,
429 you know, you just I suppose accept things and took things
430 for granted I suppose and now you think that is more
431 important so yes, remembering about things and keeping
432 certain things. I don't like too much change and I have never
433 really been bothered before about that but I am happier, it is
434 easier I suppose if things don't change that much which I
435 suppose makes sense you know, because then you get more
436 used to it, you can cope with it. So going somewhere that I
437 don't know with people I don't know and if you put all these
438 things together then I could get quite confused, in a shop I
439 can, if somewhere is really busy then that can be quite...I just
440 want to get out of there, erm I find that difficult to cope with

(left margin annotations)

presened self

Clinging on to
Self

(right margin annotations)

no point worrying
Just carry on

I can still do
photographs
I can still go out

Long: Still, years &
years - continuation
of skills/self.

Important to hold on to
what you can do *:
its a link to the past

Past more important

Cling on to who you
are

Cling: word sounds
quite desperate & as if it
is difficult to do.

Don't like change
- may this relate to
changes in self too &
link with presened
self?

Want to get out of
busy places
-why? is it confusing
or in case people see his
deficits, does he fear
people's response
or lack q resp.?

173

	441	and that was never the case, if things were busy, I didn't't	
	442	mind going to places at all but that was okay.	
	443		
	444	**I:** So how do you manage that now?	
	445		
Taking Control	446	**P:** You can decide when to go out, there is no way I would	You can decide
	447	go out to a supermarket, I can use local shops and shop on-	
	448	line and things like that. Going round a big supermarket at	
	449	Christmas would be a no, no. Before I could do that and I	
	450	didn't't mind, I was okay, I mean not that I would choose to	
	451	but you know NAME (partner) used to get, I remember from	
	452	a few years ago, before we had the internet and so we might	
	453	have had to queue half way down an aisle and he would be	change in role i partner /change in temperament?
change in self	454	the one that would really get annoyed about that and I would	
	455	be the one who thought "so what, we will get there you	
	456	know, whatever" and now that has really changed LAUGH	
	457	because I would get annoyed if I am behind someone in a	is this a parallel process? is he really annoyed with himself?
	458	shop and maybe they are fumbling for change but that could	
emotional impact (of deficits)	459	be me fumbling for change as well and I find myself really	Aware of his limitations
	460	feeling "oh for goodness sake, come on, come on" and I	
	461	know it is happening so at least I am aware that that happens	
	462	so going out when places are less busy.	
	463		
	464	**I:** What do you think the impatience is about?	
	465		
	466	**P:** I don't know. I really don't know, I just do. I am not	
Change in self	467	sure about that it just seems to have been a change in me and	a change in me
	468	I can, inside, not outside, I don't shout at people at all but	
	469	inside sometimes you are thinking and then I can be	Inside thinking – cognitive changes
	470	somewhere and suddenly something might strike me and I	
	471	think "oh, that might be you in a couple for years time, not	that may be you in a couple of years
	472	being sure what you are doing". I have found myself	– is he anticipating his decline? is he concerned he can't stop it?
	473	thinking, if we are in a shop and we are behind someone and	
	474	they are a bit confused and I am thinking that they might	

475 have what I have got you know as well and I think "calm
476 down NAME (self) be careful, be a bit understanding" so I
477 don't know but I am. Sometimes with the dog, it is not just
478 shops, it is with her or just putting the collar on her and you
479 know, I am definitely, I think that is the biggest thing I have
480 noticed and I can only put that down to the Alzheimer's
481 because things are so different to how I was before. I am not
482 sure about why that is and I don't know whether that is
483 typical or not to be honest, I am not sure about that, I am
484 putting that down to it may be not and I becoming a grumpy
485 old so on so LAUGH. Perhaps that is it LAUGH. I don't
486 know.
487
488 I: That's okay. You have spoken about a number of changes
489 in yourself and what you can do and I just wonder how that
490 impacts on you?
491
492 P: Oh SIGH. I think generally I don't feel not as confident
493 perhaps. I feel lesser, smaller because of it in a way.
494
495 I: Can you say anymore to help me understand further?
496
497 P: Erm I think that how I feel is that I don't like being ill and
498 I just feel that it just prevents me or is going to prevent me
499 from doing things so in a way I think "yes, that's it, I have to
500 accept it and do it" but at the same time erm I am feeling
501 that, I don't know, it is, I worry a bit perhaps about how other
502 people see me and even if they are being okay are they
503 thinking "oh he is loosing it a bit", or "what's up with him".
504 I suppose I get a bit bothered about what other people think
505 maybe. If I am out and about do I seem a bit strange to
506 people? I think that is what I mean, that bothers me a bit,
507 maybe I will get to a point where I don't care what is what
508 but I do, that bothers me a bit that I mind, if I am out I think

Handwritten margin notes (left):
live changed / change in self
aging
Loss Self-esteem
change in role
Feared stigma / Others view of me

Handwritten margin notes (right):
So different to how I was
becoming a grumpy old so on so.
Not as confident feel lesser, smaller
Don't like being ill – change in role from carer (a nurse)?
worried how other people see me
bothered about what people think
do I seem strange?

509 people think "he is a bit strange", I think that is what I mean

510 so I just don't feel quite as I suppose it is a confidence thing

loss of self-esteem

511 really so because I have always been very outgoing and I'm   not as out going

512 not as much I think as I was, I have not gone in on myself   not gone in on self

513 and again being with NAME (partner) and people and having

514 the dog and getting out and talking to people when I walk the

515 dog and that is why I really like that I think, a lot tend to be

516 older people and I suppose it is easier really with older   – why is it easier c̄ older people?

Aging

517 people than it is with younger ones, that is true really.   – is he identifying c̄ them more.

518

519 **I:** What is easier?

520

Preserved self

521 **P:** Talking! Yes, you can talk more about the past as well, I   talk more about the past – why is this impt?

522 tend to do that more with people who are older than me   – hold on to self

523 because it is an easier things to do, you can't really talk to   – preserved skill ↑ self-esteem?

524 younger people about the past so yes, I never thought about   – making new meaning in real time of interview.

525 that before but yes that is probably part of it, so out, meet one

526 or two people walking the dog and then you can, you can just

527 talk about all sorts of stuff and reminisce and just do that, but   reminisce

528 that is different so I don't know. I feel older, erm and I   feel older

Aging

529 haven't before at all and it's not so old but then people keep   People keep saying

530 saying I'm old, I'm fifty eight, yes fifty eight and I feel really   – is language and what people say an important exp of aging?

531 old, I suppose I am but I have never thought about age before

532 at all.

533

534 **I:** Is there something about the Alzheimer's that has made

535 you think of age?

536

537 **P:** Yes I think so.

538

539 **I:** And have you come to any conclusions as to why that

540 maybe?

541

Typical aging / associations ï old age

542 **P:** Erm, I suppose thinking about life going on and things
543 changing and that is more of a getting older sort of thing I
544 suppose, or we tend to think a bit in that way. Young people
545 get ill and that is why I remind myself that, you know, I'm
546 not that young, kids get ill, kids die which is the absolute
547 worse and then I think you are fifty eight and it has been
548 okay so far, which it has, you know I think "well yes, it's
549 true, that's fine, you know. I don't feel sorry for me, I don't
550 like that at all, I don't want to be doing that so I suppose
551 really the whole thing is still a bit mixed up, but then that is

Making sense & Reconceptualising

552 part of it as well, it's part of making sense of things and that I
553 also have to accept, that is part of the problem in making
554 sense of things. I know my uncle, his is different but he
555 doesn't make sense of anything, you know as well he is
556 really, you know quite 'gone' to be honest which is not a nice
557 way of saying it but he is okay, he seems happy but I don't
558 know so looking at that, suddenly that makes me feel..

Aging

559 Suddenly thinking about age whereas before I didn't.
560
561 **I:** How about your sense of self identity and who you are, I
562 guess some of that would have been covered in that last bit,
563 has that shifted at all?
564
565 **P:** Probably yes, its erm things have just changed so much in
566 one/two years, it is you know, things are just so different
567 from I suppose how I thought they would be CHIMING OF
568 CLOCK, that is so different itself it is just, erm, I suppose
569 sorting out where you fit into things, quite what you do now,

Redefining Self

570 erm, because NAME (Partner) has had to take so much with
571 organising having to pay the bills and all that, its not that I
572 don't know about it but it is really best that he does that but
573 then I can still help around the house, there is lots of things I
574 can do, walking the dog, helping with the house work and all
575 sorts so it is changing, it is getting used to a new routine. I

thinking of life going on & changing – this is what you do in old age?

Young people get ill – is this about normalising his exp?

actively making sense of things – reconceptua-lising?

I'm different to my uncle. why is this impt?
– diff ï of age?
– diff ï of severity: protecting / reassuring self?

things have just changed so much

different to what expected / loss of expectations.

Sorting out where you fit & what you do.

change in role

new routine – is it deeper than this? What does routine mean or signify?

Table 1. Table of initial super-ordinate and sub-ordinate themes for Malcolm

Super-ordinate themes	Sub-ordinate themes	Supportive quote	Ref. (page.line)
Self/ identity	Change in self	'I think it changes you as a person'	(1.10)
	Change in role	'he (partner) now has to organise the bills'	(17.572)
	Preserved self	'I want to carry on as normal, there are still things I can do'	(4.120)
	Clinging on to self	'you want to cling on to who you are'	(13.425)
Society/ others	Feared stigma/ others view of me	'I was a bit frightened of what people would make of it and think of me'	(7.224)
	Social loss/ isolation	'we have lost friends to be honest'	(4.107)
	Social support	'but other friends have been really supportive and are okay'	(4.115)
Coping	Taking control	'having some control or feeling you have got it is important'	(27.885)
	Making sense and reconceptualising	'it's part of making sense of things'	(17.554)
	Re-defining self	'things are so different, it's about finding out where you fit into things'	(17.568)
	Different point of view	'I am just looking at everything from a different point of view'	(9.287)
	Adjusting	'I can use local shops and shop on-line'	(14.449)
	Acceptance	'so we have accepted that'	(10.673)
	Medication	'I was pleased that there was something that might help'	(28.938)
	Diagnosis/ knowing	'I look at the computer…I actually find that helps and knowing'	(23.783)
	Talking	'talking about it helps'	(8.246)
Age	I'm too young	'people tended to be older'	(2.52)
	I'm too young to die	'young people get ill I have to remind myself that'	(17.546)
	Aging	'I feel older '	(16.531)
Loss and powerlessness	Loss of skills	'I can get lost'	(10.318)
	Loss agency	'I knew I was but it didn't quite make sense'	(10.235)
	Loss of future/ expectations	'I don't expect to live that long'	(25.840)

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Integrative analysis across cases

To begin this process the individual table of themes for each participant were compared and contrasted and a master table of themes for the sample as a whole was developed (see table 2). The integrative nature of this stage of analysis meant that some of themes included in participant's individual table of themes were not included in table 2. Using Malcolm as an example, the following sub-themes were not included in the final analysis as they emerged as less significant as a shared experience with others and as an experience for himself: diagnosis, medication and cause. The remaining themes were included although some were amalgamated and labels were modified to provide a better description of the pooled data.

Table 2: Master table of themes version 1

Super-ordinate themes	Sub-ordinate themes	Exemplar quotes	Quote location (page.line no.)
Disruption of the lifecycle	I am too young	'people usually get it in their sixties and seventies' (Emma)	(1.27)
	Aging	'I feel older' (Malcolm)	(16.531)
	Loss of adult competency	'I can't even write my own name now' (George)	(4.125)
	Contraction of life	'I don't expect to live that long' (Malcolm)	(25.840)
Disconnection	From others	'I just don't feel part of what is happening' (George)	(26. 780)
	From past self	'No that's my past – forget the past that's gone' (Peter)	(17.406)
	Contradiction: continuation of self	'the past becomes more important because you want to cling on to who you are' (Malcolm)	(13.425)
Social stigma	People think I am thick	'I think people might not want to talk to me because they think I am thick' (Emma)	(20.612)
	Loss of friends	'we have lost friends' (Don)	(4.107)
Self	Loss of self	'I used to be quite clever then all of a sudden…it just seemed to disappear' (Pat)	(6.136)
	Change in roles	'It is weird being the patient instead of caring for all the family' (Emma)	(14.412)
Loss of agency	Powerlessness	'there is nothing I can do about it and that hurts a lot' (Pat)	(7.156)
	Dependency	'I have to rely on my son to take me' (Peter)	(10.226)
	Future decline	'You have to play the cards you've been dealt' (John)	(19.44)7

Table 2: Master table of themes version 1 continued

Super-ordinate themes	Sub-ordinate themes	Exemplar quotes	Quote location (page.line no.)
Reviewing and reconnecting	Adopting a different view	'there are far more people in far more difficult situations' (Mark)	(2.38)
	Reconnecting with others	'I am not going to lock myself in you know' (Don)	(19.451)
	Reconnecting with self	'I just want to get back on an even keel and get into doing something that makes me happy and gets me out' (Emma)	(7.210)
	Re-engaging in life	'I don't want to be a cabbage I want to be doing something' (Peter)	(25.608)
Control	Regaining control	'You have got to be positive and go for it' (Mark)	(9.292)
	Fighting talk	'If it gets tough I get tougher than that' (George)	(21.634)
	Preserving skills	'You see I am quite capable' (John)	(24.590)

Writing up

With time and continued reflection themes from the integrative analysis across themes were revised. It became apparent from repeated engagement with the interview material and from version one of the master table of themes (table 2) that there was another layer of interpretation. This new level of data analysis provided a more coherent representation of the data and was a topic that was discussed in detail during the quality control checks and during supervision. It emerged that a number of the super-ordinate themes lay on a continuum with the experience of living with AD on one end and attempts to cope with the experience on the other (e.g. loss of agency and regaining control; disconnection and reconnecting). As such, the themes were re-organised to reflect this pattern (see table 3).

Consequently some super-ordinate themes became sub-themes as the level of interpretation deepened (i.e. disconnection became a sub-theme of social orientation). Disruption of the lifecycle remained although reviewing was added as a sub-theme as this appeared to relate to a reviewing of age-related expectations. The significance of the impact on self and the dichotomy of how people respond to the threat to self (to cling on or re-define) was demonstrated more coherently in this new presentation. Some sub-themes were merged in the reorganisation as additional connections between them were highlighted. The revised master table of themes and the final version of analysis used for writing up was thought to show the relationships between the lived experience and coping more transparently.

Table 3: Master table of themes final version

Super-ordinate themes	Sub-ordinate themes	Exemplar quotes	Quote location (page.line no.)
Disruption of the lifecycle	I am too young	'people usually get it in their sixties and seventies' (Emma)	(1.27)
	Aging	'I feel older' (Malcolm)	(16.531)
	Loss of adult competency	'I can't even write my own name now' (George)	(4.125)
	Contraction of life	'I don't expect to live that long' (Malcolm)	(25.840)
	Reviewing life expectations	'I think I have taken on a different style [of coping]' (John)	(16.385)
Identity	AD: a threat to self	'it changes you as a person' (Malcolm)	(1.10)
	Stigma	'it is a stigma to being an older person…it is meant to be for older people' (Emma)	(9.249)
	Loss of self-worth	'I must be useless' (Pat)	(14.333)
	Holding on to self	'you want to cling on to who you are' (Malcolm)	(13.425)
	Redefining self	'Your past life is past. That is gone now - just forget it' (Peter)	(22.516)
Social orientation	Disconnection & isolation	'I just don't feel like I am part of what is happening' (George)	(26.720)
	Reconnecting	'I am not going to go and lock myself in' (Don)	(19.451)
Agency	Powerlessness & loss of agency	'there is nothing I can do about it and that hurts a lot' (Pat)	(7.156)
	Regaining control	'You have got to be positive and go for it' (Mark)	(9.292)

<u>Appendix O. Exerts from the Researcher's Reflexive Journal.</u>

Initial reflections on potential researcher bias

I am a trainee clinical psychologist in my late twenties. I have experience of assessing and working with people with dementia through working into older adult services (for people 65 years and older) including a community mental health team and a specialist memory service. From this work I became aware of a common acceptance of AD being something that accompanies 'old age'. Thus I became interested in how people younger than 65 – who may not be typically construed as having reached 'old age' - make sense of and cope with having the disease.

From my clinical experience I expected the loss of employment and driving to be particularly poignant. This expectation may also be influenced by the importance I attach to these areas of life as someone young in their career and family life. I was also aware of the high value that I placed on my health in terms of it allowing me to continue doing the things that are important to me. As such, I expected that developing a progressive disease in younger life would be devastating both for the person themselves and those important to them.

Clinically, I have an interest in psychodynamic psychotherapy approaches and as such I have experience in making interpretations of meaning from discourse. I was conscious not to make interpretations of the data too quickly and to try to stay with participants' accounts to develop a number of conceptual ideas prior to interpretations.

Attempts to bracket off

In an attempt to keep the analysis grounded in the interview data rather than being influenced by studies in similar areas such as chronic illness or coping in older people with dementia I did not complete the larger literature review until the writing up of the analysis was complete. Some research into the area had to be completed for the development of the proposal in November 2008; however significant time had lapsed for this to not dominate the analysis. Furthermore, the researcher had not sort to become an expert in such coping models at this stage.

To apply IPA successfully, however, one is required to draw on psychological knowledge to facilitate the interpretation of meaning. As can be seen in the findings, theories relating to lifecycle and grief were drawn on in the analysis. Great care was taken to ensure that the application of these theories emerged from the data rather than vice versa and time was dedicated to discussing this in quality checks and supervision.

The reflexive process

Reflexivity was approached as a process that continued and developed throughout the research. Although it was tempting to complete the interviews in a short period of time once it was clear that people were interested in participating in the study care was taken to pace the interviews to allow for reflection. This meant that the researcher could highlight additional themes to be explored in subsequent interviews and allowed her to reflect on and improve her interviewing skills. It also allowed more scope for purposive sampling in which the researcher could

work with the recruitment sites to sample people with similar characteristics or

experiences.