Volume I: Research Component

Older women's experiences of living alone with Dementia

By

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A thesis submitted to:

The University of Birmingham
For the partial fulfilment of the degree of

Doctorate in Clinical Psychology

Department of Clinical Psychology
School of Psychology
The University of Birmingham

June 2009

Acknowledgements

I would like to thank my supervisors, Drs Jan Oyebode, and Adam Cleary for all their enthusiasm, knowledge and wisdom. I would like to thank the staff at the Older Adult Service of Birmingham and Solihull Mental Health Foundation Trust for helping me recruit participants. Above all, I would like to thank the eight women who form the basis of this study, for giving of themselves freely and honestly. Thanks to my friends, family and fellow trainees. Finally thank you to my partner Marco, for your love, patience and encouragement, and also to my grandmothers, to whom I dedicate this thesis.

Overview

Volume I

The research volume comprises two papers which focus on the experience of living alone in older adults, the aim being to highlight them as a group of people, and encourage further important research.

The literature review synthesises current research on the well-being of older adults living alone. Fifteen papers were identified, which include comparing well-being and loneliness in older adults living alone with those living with others, exploring the experiences of older women living alone, looking at predictors of quality of life in those living alone, looking at the impact of social networks and illness on well-being, and the impact of being house-bound on sense of self. The articles are heterogeneous in nature, reflecting the confusion in the literature surrounding the concepts of well-being, quality of life and life satisfaction. From the papers one can conclude that in general, living alone appears to have a negative impact on well-being, though not exclusively. Further research is suggested to explore the personal experiences and meanings of their lives to individuals who live alone.

The empirical paper explores how women with dementia who live alone manage their sense of self and cope with the illness. Eight women were interviewed to explore how they managed their identities and coped in the absence of a significant co-resident other who might reflect them back to themselves. Interpretative Phenomenological Analysis was used to analyse the transcripts. From the individual themes, master themes emerged about loss, embodiment, adapting, awareness, safety, relationships, exclusion and loneliness. The women appeared to be actively engaged in re-constructing their sense of self using a variety of coping strategies. Their relationships with others, particularly friends, neighbours and attendance at memory clubs were important in enabling connection and safety. Memory loss was mostly significant through loss of independence along with a desire for meaningful relationships.

Volume II

This volume presents five clinical practice reports (CPRs). CPR 1 discusses work with a man with depression and anxiety about taking antidepressants, formulating his problems from two different theoretical perspectives. CPR 2 presents findings of a small scale service project of a focus group exploring the experiences of service users' of an assertive outreach service. CPR 3 is a single case experimental design of an assessment, formulation and intervention of a four year old girl with encopresis and enuresis. CPR 4 is a case study of an older man with depression using a systemic (narrative) framework. CPR 5 is a case study of psychodynamic work with a young woman. This was an oral presentation, with the abstract provided.

Contents

Volume I

Page

Literature Review

The impact of living alone on older adults: a systematic review

Empirical Paper

How older women who live alone with dementia make sense of their experiences: An Interpretative Phenomenological Analysis

Volume II

CPR I: Psychological Models

Title: The case of a 51 year old man with recurrent episodes of depression who is afraid to stop taking antidepressants

Page

CPR II: Small Scale Service Related Project

Title: Findings from a focus group exploring the experiences of service users from an assertive outreach team

CPR III: Single Case Experimental Design

Title: Assessment, Formulation and Intervention with a four year old girl with encopresis and enuresis

CPR IV: Case Study

Title: ‘When the Green Slimy Bugger entered my life’

CPR V: Oral Presentation

Title: Working in the Transferences: Assessment, Formulation and Intervention with Suzie

The impact of living alone on the well-being of older adults: a systematic review

Literature review submitted for the Degree of
Doctor of Clinical Psychology

Prepared for submission to ‘Dementia: The international journal of social research and practice’

6417 words

Abstract

This review aims to critically evaluate the recent literature on the impact of living alone on the well-being of older adults. A literature search was completed in order to identify relevant peer reviewed articles. Fifteen studies were reviewed, forming a heterogeneous group which included: comparing well-being and loneliness in older adults living alone with those living with others, exploring the experiences of older women living alone, predictors of quality of life in those living alone, investigating gender differences, comparing rural with urban living, the impact of social networks and illness on well-being, and the impact of being house-bound on sense of self. Conflicting evidence emerges. In general, living alone appears to have a negative impact on well-being, though not exclusively. Further research is suggested to explore the personal experiences and meanings of their lives to individuals who live alone.

Introduction

The number of elderly people is expected to increase in the UK and most other Western countries. The proportion of people living alone in the UK has doubled from 6% of the population in 1971 to 12% in 2008 (ONS, 2008a). In 2006 11.3 million were over State Pension Age, up 420,000 since 2002 (ONS, 2008b), 7.2 million women were aged 60 and over, 9.7 million people were aged 65 and over, of whom 5.5 million were women; 2.7 million were aged over 80, up 220,000 since 2002 (ONS, 2008a). Population projections indicate that by 2031 there will be more than 1.1 million people aged 90 and over in Great Britain. Of those aged 80 and over living alone 72% are women (ONS, 2008a). It is not known how living alone affects older peoples' mental well-being, but population surveys undertaken so far suggest it may have an impact. An ELSA Age Concern report (2008), for example, found life satisfaction is higher for older people living with others than for those living alone, even though they have worse physical health.

Various factors are known to be associated with the well-being of people living alone, and this has been reflected in the focus of the extant literature. Gender differences have been investigated by Age Concern (2008), who found amongst women, 54% of those living alone perceived their health as fair/poor compared with 32% of those living with others, with this difference not found in men, although men aged 80 and over living alone report higher loneliness than those not living alone. Women have been found to suffer more from multiple social exclusion than men, possibly due to their greater longevity (Age Concern, 2008). Divorced and never-married women who live alone have been found to be at greater risk of poverty and have poorer quality housing (Carp, 2001).

Some research has been undertaken to investigate depression in those living alone - some found living alone results in increased depression (Shulman, Gairola, Kuder & McCulloch, 2002), while others found those living with others reported higher levels of depression (Gustavson & Lee, 2004).

There is reason to believe that some significant sub-groups of older people may be at risk of poor well-being if living alone, for example, those living alone with dementia may be particularly vulnerable. Webber, Fox & Brunette, (1994) found people with dementia who lived alone were more likely to be female, older and poorer. In comparison to people with dementia living with others, they were less likely to use hospital, day centre or nursing home care or see physicians on a regular basis. Fratiglioni, Wang, Ericsson, Maytan & Winblad (2000) found reduced social networks and living alone played a negative role in the development of dementia, with Fratiglioni et al suggesting lack of social network as a risk factor for the development of dementia.

On the other hand, there may be some reasons to surmise that those used to living alone could have protected well-being, for example single women have larger social networks than those who are married. Ageism might have less impact for people living alone. In addition, people living alone may possibly have greater opportunities for pursuing their own interests, and may be able to pursue their lives without relationship problems, marital discord or carer responsibilities.

In research there is sometimes conflation between the concepts of living alone and loneliness. In much of the earlier literature the concepts of living alone, loneliness and social isolation were used interchangeably (Townsend, 1968); with social isolation assumed in some studies if an older person lived alone (Tunstall, 1966). However, living alone and experiencing loneliness do not necessarily mean the same thing (e.g. de Jong-Gierveld, Kamphus, & Dysktra, 1987; Weiss, 1987). de Jong-Gierveld, Kamphus, & Dysktra (1987) found people living alone often experienced more loneliness than those living together with a partner. However, Weiss (1987) suggested *experienced* loneliness involved both emotional loneliness and social isolation. For example, some individuals may be isolated but not lonely, others both isolated and lonely (Wenger, 1983). Thus living alone may be seen as a type of independent variable, whilst loneliness is an outcome.

Though possibly controversial, a broad definition of well-being which includes quality of life (QoL) is used in this review. This is because deconstructing the concepts is problematic - the literature on well-being and QoL reflects both macro-societal and socio-demographic influences in addition to the characteristics and concerns of individuals (Gabriel & Bowling, 2004). There are multiple models of QoL (see Gabriel & Bowling, 2004 for detailed discussion).

Purpose of Review

The aim of this review is to establish whether recent research undertaken since a previous review (Victor, Scambler, Bond & Bowling, 2000) provides evidence that living alone has an impact on older people's well-being. The review seeks to understand whether particular patterns can be seen in terms of well-being in those living alone, and to review the evidence on the impact of living alone on individuals over time.

Methodology

Search Strategy

The review identified journal articles published between 2000 and 2009 in the English language. Articles published before 2000 have been reviewed previously by Victor et al (2000) and so these were not included in this review. This review builds on that of Victor et al, which looked at the three concepts of: loneliness, social isolation and being (and living) alone in older people, and the research evidence for these. This review differs in rationale, in investigating living alone in older adults, and the consequences of this on well-being. A further review was conducted by Hays in 2002, although she reviewed the evidence in support of a proposed model, rather than conducting a systematic review of the literature. The inclusion criteria for the current study were that:

- The study related to older people rather than including only older people as an undifferentiated part of a wider sample
- The concept of living alone was explored or discussed
- The study recorded a form of outcome measure related to well-being or loneliness

- The study was published in a peer reviewed journal
- Study populations and research was undertaken in European or Western industrialised technological countries (eg USA, Australia)

Electronic databases were searched, while relevant books, journals and abstracts were searched manually. The databases providing papers of greatest relevance were Psychinfo, Pubmed, ASSIA and CINAHL. The search terms were grouped into three categories: older adults/elder*/age*ing; living alone/living arrangement*; well-being/quality of life/life satisfaction. Articles were excluded if their focus was on depression or cognitive decline and if factors related to these concepts were used as outcome measures. Articles meeting the inclusion criteria were identified in two stages. Initially each abstract was scanned to make a judgement regarding its suitability for inclusion, after which full length texts were obtained. At the second stage, each article was read in full. Due to the heterogeneity of the studies, a meta-analysis was not feasible (Centre for Reviews and Dissemination, 2001). A qualitative critique and synthesis of the studies was consequently conducted.

The Studies

Fifteen studies were reviewed and are summarised in Table 1.

Table 1. Studies included in Review

N	Reference	Title	Participant	Methodology	Country	Well-being	Outcomes
1	Qu & Weston (2003)	Ageing, living arrangements and subjective wellbeing	N=1850 age 65+ Men and women	Census data Old versus young and older adults living alone compared with living with others SF-36 measure of wellbeing	Australia	Well-being	Most had high satisfaction with life. Vitality and social functioning as good in 65-74 age groups as 55-64 years. 75+ had poorer health on all measures except mental health. Those living alone had significantly lower wellbeing in some areas: financial circumstances, women more likely to say physical health interfered with ability to undertake everyday activities. Men more vulnerable to loneliness and dampened satisfaction with life.
2	Hellstrom et al (2004)	Quality of Life and symptoms among older people living at home	N=1248 Age 75+ Men and women	Compared people receiving help with those not receiving help. Living alone not main variable, mainly those receiving help.	Sweden	Quality of Life (QoL)	Group receiving help had significantly higher age, more women, more widowed, living alone, greater inability to remain alone at home and lower QoL. Living alone, being unable to remain alone at home without help and fatigue were predictive of

				Age stratified random sample. Cross sectional survey design, postal questionnaire: Life QualityGerontological Centre Scale, Lund. Chi square, t-test, mann whitney: differences between groups.			low QoL among those receiving help.
3	Victor et al (2005)	The prevalence of, and risk factors for, loneliness in later life: a survey of older people in Great Britain	N=999 Older people 65+ years Men and women	Living in own homes, living alone not main variable. 1/3rd (37%) lived alone. Interviewer-administered survey (Omnibus) ONS on QOL; Derivative measure (UCLA	UK	Loneliness	Strong relationship between loneliness and being female, widowed, living alone, aged 75+ years, health factors (physical, mental ill-health), material resources, and limited ‘social’ resources (time alone, availability of confiding relationships). No association with levels of social contact or proximity to children, friends and family. Quality rather than

				loneliness scale). Self-assessed loneliness. Chi Square; GHQ, regression modelling			number of relationships suggested as causative factor. 85+ years lowest risk loneliness. Six vulnerability factors for loneliness identified: marital status, increases in loneliness over previous decade, increased time alone over previous decade, elevated mental morbidity, poor current health & poorer health in old age than expected. Advanced age and possession of post-basic education protective of loneliness. 3 loneliness pathways proposed.
4	Scharf & de Jong Gierveld (2008)	Loneliness in urban neighbourhoods: an Anglo-Dutch comparison	Older people aged 60+ N=501 from UK, 3508 from Netherlands	Don't introduce living alone as main variable. Loneliness scale Multiple classification analysis on empirical data from UK and Netherlands.	UK and Netherlands	Loneliness	13% UK and 4% Netherlands participants severely lonely. Quality of residential neighbourhood accounted for large degree of variance in both countries. More widowed in 75+ age group compared to younger, and associated with higher percentage living alone. Higher proportion of living alone

				Longitudinal NESTOR survey			individuals in deprived areas, along with those widowed, divorced, separated or never married. Those living with partner lower loneliness scores than living alone, particularly men. Loneliness scores lowest for those integrated into community.
5	Walker and Hiller (2007)	Places and Health: a qualitative study to explore how older women living alone perceive the social and physical dimensions of their neighbourhoods	Women Aged 75 - 93 N=20	Qualitative – in depth interviews. Grounded theory. All living alone	Australia	Satisfaction & security with neighbourhood Wellbeing	Reciprocal and trusting relationships with neighbours underpinned women's sense of satisfaction with and security in neighbourhood. Living in close proximity to services, and existing social networks also seen as important. Women living in disadvantaged areas more conscious of social disconnection in their neighbourhoods and impact of traffic and pollution on environment.
6	Iliffe et al (2007)	Health risk appraisal in older people 2: the	N=2598 65+ years	Cross sectional study. Secondary	UK	Social isolation	Risk of social isolation associated with older age, living alone, depressed mood, poor memory, fear

		implications for clinicians and commissioners of social isolation risk in older people		Multivariate analysis from RCT. Questionnaire: Lubben Social Network Scale, Health Risk Appraisal-Older Instrument, Mental Health Inventory Screening Test.			of falling, worse functional ability and self rated fair or poor health. 190 out of 397 potentially socially isolated people lived alone.
7	Wenger & Burholt 2004	Changes in levels of Social Isolation and Loneliness among Older People in a Rural Area: A Twenty-Year Longitudinal Study	85-102 years old. Mean age 93 N=47 15 males, 32 females	Longitudinal study over 20 years (1979-1999). Customary measure of loneliness. Aggregate measure of loneliness and isolation. Quantitative and qualitative data. Majority living	Wales	Loneliness and social isolation	Those neither isolated nor lonely were all married throughout, none lived alone. Mostly married men with children living nearby. Most common category became more isolated and lonely over course of study due to becoming housebound with reduced social contact. Those not isolated but lonely mostly due to deterioration in health, but had wider social network. Isolated but lonely

				alone			group all childless- personality characteristics hypothesised. Social networks mainly neighbours. Some overcame loneliness and social isolation through changes in life choices
8	Michael et al (2001)	Living Arrangements, Social Integration, and Change in Functional Health Status	Women aged 60-72 years N= 28,324	Between group, living alone v living with others. Nurses health study. Mediating variables. Longitudinal study: change in functional health status over 4 years. QOL questionnaires; SF-36 (health status), logistic regression	USA	Emotional well-being Mental health/ vitality	Women living alone had lower risk of decline in mental health and vitality compared to those living with a spouse. Contact with friends and relatives and level of social engagement were significantly protective against a decline in mental health amongst women living alone but not those living with a spouse.
9	Hellstrom and Hallberg	Perspectives of elderly people	75+ years N=448	Postal Questionnaire, sex, age,	Sweden	Quality of Life (QoL)	Those with musculoskeletal pain, abdominal pain, loss of appetite, constipation,

	(2001)	receiving home help on health, care and quality of life		living conditions. Age stratified randomised sample. Quantitative: chronbach's alpha, Mann-Whitney, Kruskal Wallis, regression			dyspnoea, fatigue, sleep problems, anxiety, nervousness, depression, and feeling lonely had lower QoL than those without these problems. Age, number of complaints, living alone and the ability to be alone were significantly associated with low QoL.
10	Baldock & Hadlow (2002)	Self-Talk versus Needs-Talk- an exploration of the experiences of housebound older people.	75+ years N= 38 (29 female, 9 male)	Qualitative (grounded theory), within group, living alone and housebound from 'Growing Older' Sample. Measures: GHQ, Bartel index, Coleman scales (strength of self esteem) & life course interview (assessment	UK	Self esteem	Differences found between users and providers of healthcare, and their conceptions of an acceptable quality of life. The experience of disability and living alone re-ordered the criteria by which people judged their quality of life. The order of positive sources of self-esteem were dominated by 'inner self', followed by 'family', 'interests', 'others' and 'health'. Inner emotional and intellectual resources were the dominant source of high self-esteem followed by support from a family member.

				continuities and discontinuities in sense of self)			Participants' views of services were mediated by their conceptions of self. A minority reported being lonely.
11	Pinquart (2003)	Loneliness in married, widowed, divorced and never-married older adults	N= 4043 older adults Aged 60+ years	Between group comparisons 2/3rds unmarried and living alone 60% women. Quota sampling procedure 11 item Rasch- based loneliness scale (de Jong-Gierveld) Questionnaire. Hierarchical linear modelling (regression analysis)	Germany	Loneliness	Married adults reported lower levels of loneliness than other groups. Widowed adults had lower levels of loneliness than divorced adults. Men reported higher levels of loneliness than women in the divorced, widowed and never-married groups. Divorced and never-married men reported highest levels of loneliness. No sex differences were found in married adults. Contacts with adult children, siblings, friends and neighbours were more likely to reduce loneliness in unmarried than married adults. Childless unmarried adults benefited from contact with siblings and friends, but not for unmarried parents.
12	Holmen et	Social and	N=589	Between	Sweden	Loneliness	Non-demented elderly

	al (2000)	emotional loneliness among non-demented and demented elderly people	Aged 75+	group - living alone compared with living with others & demented versus non-demented. Structured interviews (questionnaire) using UCLA loneliness scale			participants reported being lonely significantly less than demented participants, but there were no differences in the emotional experience of loneliness. Social loneliness was more common in the different levels of dementia and increased with reduced cognitive functioning, while emotional loneliness decreased. Living with others and in one's own apartment showed a positive influence on feelings of loneliness.
13	Schnittker, J. (2007)	Look (Closely) at All the Lonely People: Age and the Social Psychology of Social Support	N=2398 (variable according to model) 24+ years	'American Changing Lives' survey. Longitudinal interviewed at 3 points in time. Asked about negative support in 2 time points, asked about no of confidants,	USA	Loneliness	Four theoretical models tested. The likelihood of reporting no close friends or confidants increases with age - role changes (eg living alone) account for much of this increase. However these cases are exceptional and in general the number of friends and confidants stays the same. Age-related changes in well-being reflect the kinds

				positive support and loneliness at all 3 time points. Living arrangement controlled for. Quantitative data: regression models			of roles and environments that age groups find themselves in. Older people more vulnerable to social isolation and loneliness because more likely live alone, and losing roles that were once vital to social integration. Evaluations of support become more positive with age and loneliness declines.
14	Bowling et al (2003)	Let's Ask Them: A National Survey of Definitions of Quality of Life and its Enhancement Among People Aged 65 and Over	N=1323 65+ years	Omnibus (national) Survey. Longitudinal over 12 months at quarterly intervals. QoL questionnaire – structured questions and scales + open ended questions. Themes coded. 1/3rd lived alone, most white.	UK	Quality of Life	Deteriorating health and consequent social handicaps reported to have led to depression in some, and fears for the future, especially in those living alone. Two most frequently reported areas of QoL most important were having good social relationships (family/marriage/friends/neighbours/pets) and good health. Social relationships reported most important to those widowed/divorced/separated. Wide range responses re: meaning of QoL.

				Described as quantitative, (a form of content analysis) which they state is not qualitative research.			
15	Cattan et al (2003)	Alleviating Social Isolation and Loneliness among Older People	N= 25 individual interviews + 22 in focus group. 55-94 years old	Majority lived alone and widowed. Case study design; qualitative in-depth interviews + quantitative. Purposive sampling from preceding survey of health promotion activity. Interviewed project staff and older adults. 22 focus group interviews with	UK	Loneliness and social isolation	Practitioners and older people define social isolation and loneliness differently, with a disparity between the two groups' perceptions of acceptable interventions to prevent this. Living alone and being housebound perceived as major causes of social isolation and loneliness

				older adults + 25 individual interviews. Framework analysis			

In order to judge the quality of the research findings, each study was reviewed in relation to a number of factors, each of which is considered important in the production of reliable and valid research. To assist in the evaluation of the papers, a ‘Quality Assurance Criteria Checklist’ (Table 2) was adapted from the review criteria recommended by the American Academy of Neurology Clinical Practice Guidelines (2004). Included within this were elements of the research studies’ theoretical basis, design, measures, sample, analysis and results. Each item was rated Y = Yes, N = No, P= Partial. This provided guidance on the overall quality of each paper. It can be seen from the table that the studies vary considerably in whether they meet the relevant criteria, with the qualitative studies in particular seeming to give too little information for definite conclusions to be drawn about their quality. All are discussed in richer detail in the text below, where each factor is considered in relation to the fifteen studies included.

Table 2. Quality Assurance Rating

Rationale and Design	Scharf & De Jong Gierveld (2008)	Victor et al (2005)	Walker & Hiller (2007)	Schnittker (2007)	Iliffe et al (2007)	Bowling et al (2003)	Wenger & Burholt (2004)	Cattan et al (2003)
Was there a theoretical/conceptual basis for the study?	Y	Y	Y	Y	Y	Y	Y	Y
Were aims and objectives clearly presented?	Y	Y	Y	Y	Y	Y	Y	Y
Was the methodology described in a clear manner that would allow replication?	Y	Y	Y	Y	P	Y	Y	N
Is the study longitudinal?	Y	N	N	Y	N	Y	Y	N
If so is it for a period of more than a year?	Y			Y		N	Y	
Did the study use a control (comparison) group?	N	N		Y		N	N	N
If so, were initial group differences accounted for?				Y	Y			
Were participants systematically selected (eg to be representative of a particular population)?	Y	Y	P	Y	P	Y	Y	Y
Is the study qualitative in design?	N	N	Y	N	N	N	Y	Y
If so, was a specific method chosen?			Y				N	Y

Was the specific method justified?			N				Y	P
Was it well described?			P				Y	P
Sample and Measures								
Were reliable and valid measures used to measure wellbeing/loneliness/depression?	Y	Y		Y	Y	Y	P	N
Was the sample homogenous in terms of age, living situation and other demographic factors?	N	Y	Y	Y	Y	P	N	P
Were appropriate outcome measures used to assess the variables of interest in the study?	Y	Y		Y	Y	Y	P	P
If qualitative, was the sample appropriately situated (described in enough depth)?			P				P	P
If qualitative was the sample appropriate to the method chosen?			Y				Y	Y
If qualitative were an appropriate number of participants included?			Y				Y	Y
Results								
Were confounding variables controlled for?	Y	Y		Y	Y	P	P	N
Were suitable statistical	Y	Y		Y	Y	Y	P	N

analyses employed?								
Was the sample size enough to detect meaningful effects?	Y	Y		Y	Y	Y	P	N
Are the results generalisable?	P	Y		Y	P	Y	P	N
Qualitative Studies								
Were the analytic steps described?			P				N	Y
Is the research repeatable?			P				P	P
Is the research credible? (plausible?)			P				Y	Y
Were quotes given?			Y				N	Y
Does the researcher demonstrate trustworthiness?			P				P	Y
Was reflexivity demonstrated?			P				N	P
Is the study transferable?			P				N	Y

Rationale and Design	Michael et al (2001)	Hellstrom & Hallberg (2001)	Baldock & Hadlow (2002)	Pinquart (2003)	Holmen et al (2000)	Hellstrom et al (2004)	Qu & Weston (2003)
Was there a theoretical/conceptual basis for the study?	Y	Y	P	Y	Y	Y	Y
Were aims and objectives clearly presented?	Y	Y	Y	Y	P	Y	Y
Was the methodology described in a clear manner that would allow replication?	Y	Y	N	Y	N	Y	N
Is the study longitudinal?	Y	N	Y	N	N	N	N
If so is it for a period of more than a year?	Y		N				
Did the study use a control (comparison) group?	Y	Y	N	Y	Y	Y	Y
If so, were initial group differences accounted for?	Y	P		Y		Y	P
Were participants systematically selected (eg to be representative of a particular population)?	Y	Y	Y	Y	Y	Y	P
Is the study qualitative in design?	N	N	Y	N	N	N	N
If so, was a specific method chosen?			Y				
Was the specific method justified?			P				

Was it well described?			N				
Were reliable and valid measures used to measure wellbeing/loneliness/depression?	Y	P		Y	Y	P	P
Sample and Measures							
Was the sample homogenous in terms of age, living situation and other demographic factors?	Y	Y	Y	Y	Y	Y	Y
Were appropriate outcome measures used to assess the variables of interest in the study?	Y	Y		Y	Y	Y	P
If qualitative, was the sample appropriately situated (described in enough depth)?			P				
If qualitative was the sample appropriate to the method chosen?			Y				
If qualitative were an appropriate number of participants included?			Y				
Results							
Were confounding variables controlled for?	Y	Y		Y	P	Y	P
Were suitable statistical analyses employed?	Y	Y		Y	Y	Y	N
Was the sample size enough to detect meaningful effects?	Y	Y	Y	Y	Y	Y	Y

Are the results generalisable?	Y	Y		P	N	Y	P
Qualitative Studies							
Were the analytic steps described?			N				
Is the research repeatable?			N				
Is the research credible?			P				
Were quotes given?			Y				
Does the researcher demonstrate trustworthiness?			P				
Was reflexivity demonstrated?			P				
Is the study transferable?			N				

The studies have been divided into two sections: those that focus on the association between living alone and the outcomes of loneliness and social isolation, and those which focus on the links between living alone and well-being, quality of life or self esteem. They shall be discussed and critiqued within the two sections. However, prior to that two general matters, i.e. cultural contexts and characteristics of samples, will be highlighted.

Cultural context

Six studies were conducted in the UK (one specifically in Wales), one in the UK and Netherlands, two were conducted in Australia, two in USA, three in Sweden and one in Germany. Findings from each country will be influenced by its particular culture and so studies not undertaken in the UK will be limited in their applicability to a UK population as compared to UK based studies.

Study Participants

The number of participants in the studies varied considerably from 20 in a qualitative study on older women’s perceptions of neighbourhood (Walker & Hiller, 2007) (5 – see table 1), to 28,324 in a large scale study investigating living arrangements, social integration and change in functional health status of women (Michael, Berkman, Colditz & Kawachi, 2001) (8). Eight studies had sample sizes of more than 1000 participants (1,2,4,6,8,11,13,14); the three qualitative studies each contained less than 47 participants (5, 7, 10) with Wenger & Burholt (2004) (7) also consisting of quantitative data. For qualitative studies smaller numbers are more acceptable, however with quantitative studies larger sample sizes are necessary in order for them to be reliable and valid. The characteristics of the study participants also varied. The majority included both men and women, with two studies consisting of women only (Walker & Hiller (2007) and Michael et al (2001) (5 & 8)). For further demographic detail see Table 1.

Studies focusing on Loneliness and Social Isolation

Eight studies (3, 4, 6, 7, 11, 12, 13, 15) used loneliness as a key variable in their investigation. Victor, Scambler, Bowling, & Bond (2005) (3) looked at the prevalence of, and risk factors for loneliness in later life; Scharf & de Jong-Gierveld (2008) (4) compared loneliness in urban neighbourhoods in the UK and Holland; Iliffe et al (2007) (6) explored the significance of social isolation in the older population for GPs and commissioners. Wenger & Burholt (2004) (7) investigated loneliness in older people living in a rural part of Wales, while Cattan, Newell, Bond & White, (2003) (15) explored the relationship between older peoples' and practitioners' perceptions of social isolation and loneliness, and their concepts and judgements of acceptable services to prevent this. Pinquart (2003) (11) looked at predictors of loneliness in married, widowed, divorced, and never-married older adults (the latter three groups all lived alone) in Germany; Holmen, Ericsson & Winblad (2000) (12) compared loneliness in "demented" and "non-demented" participants and the impact of living alone versus living with others on loneliness in Sweden. Finally, Schnittker (2007) (13) explored the relationship between age and social support using three theories. In the sections that follow the designs and main findings of the studies will be described, followed by a critique of the quality of the research and consequent weight that can be placed on each paper's findings.

Design

Most of these studies used a cross sectional methodology (3, 4, 6, 11, 6, 15). (7,12 & 4) describe themselves as longitudinal studies; Wenger & Burholt (2007) (7) exploring changes in loneliness and social isolation over twenty years with follow up every four years, Holmen et al (2000) (12) did not state the timescale of the project, and Scharf & de Jong-Gierveld (2008) (4) describe cross-sectional rather than longitudinal data. (11, 12, 6, 4, 3) obtained data via questionnaire, while (4, 11, 6, 3,7) used a survey method. Wenger & Burholt (2007) (7) used quantitative and qualitative data (questionnaire with open-ended questions, verbatim comments). Cattan et al (2003) (15) used quantitative and qualitative data in the form of a case study.

Cross sectional versus longitudinal studies

Most of these studies are cross-sectional designs which render them unable to determine causality, particularly in relationships between social isolation, depression and perceived decreasing functional ability, as in Iliffe et al (2007). However Illiffe's study was a secondary analysis of data from a large scale Randomised Controlled Trial (RCT) which adds more weight to the significance of their findings as compared to the smaller scale studies. However, in aiming to exclude variables in order to obtain homogeneity of data, Iliffe et al did exclude disabled older people and therefore the prevalence of health problems found in their study may be lower than the general older adult population. They do not clearly describe the methodology, stating it is described in other papers which are not reviewed, making it difficult to accurately critique their paper and limiting the strength of it being an RCT. Participants were a self-selected sub-group who returned lengthy questionnaires and hence the extent of social isolation may also be underestimated, since those who did not complete the questionnaire were significantly more depressed.

Longitudinal studies such as that undertaken by Wenger & Burholt (2004) overcome many of the methodological difficulties of cross sectional studies which are undertaken at one point in time, and thereby only give a ‘snap-shot’ of insight into peoples’ lives. They found most individuals became more isolated and lonely over the course of the study due to becoming housebound with reduced social contact. The cohort, though small (N=47), was followed up every four years for over twenty years. Methodological weaknesses of this study were that quantitative comparisons of loneliness and social-isolation were actually only made at eight year intervals, although they state qualitative data is available at all measurement points. Crude aggregate measures were used, although they argue a difficulty with longitudinal studies is using the same measurements throughout in order to maintain comparisons. Other changes in the variables of interest may also have occurred between measurement points. Individuals living alone were also not clearly demarcated and hence did not appear to form an undifferentiated group, making it difficult to make clear comparisons. However the longitudinal nature of the study over a long timescale, is a significant strength, thereby allowing real changes over the life-course of individuals to be traced, along with the attempt to aggregate qualitative and quantitative data.

Definitions of loneliness

Schnittker uses the concepts of loneliness and well-being interchangeably which is problematic since they are clearly different. Pinquart discusses definitions and types of loneliness and hypothesised causative factors, differentiating social and emotional isolation, and assumptions in the literature that quality of contact is more important for well-being than quantity. Cattan et al (2003) found practitioners and older people define social isolation and loneliness differently, with a disparity between the two groups' perceptions of acceptable interventions to prevent this. Practitioners defined loneliness broadly, whereas older adults made clear distinctions between types of loneliness, suggesting they require different types of action. Interviewees suggested the nature and quality of peoples' social networks affected the likelihood of them moving out of the perceived negative state. As discussed by Victor et al, interviewees in one-to-one interviews were often reluctant to admit being lonely, but used the term to describe others, which was hypothesised to be due to stigma of what is considered a social failure.

General Findings

Living alone was found to be associated with loneliness in most studies. Scharf & de Jong-Gierveld (2008) found those living alone were more lonely than those living with a partner, especially in those aged over 75 years. Iliffe et al (2007) also found the risk of social isolation was associated with older age and living alone, along with a number of other factors (see Table 1). Iliffe et al suggest living alone is significantly associated with risk of social isolation, which is hypothesised to reflect the loss occurring when a partner dies, though they state that living alone should not be used as a proxy for social isolation risk. Cattan et al (2003) found living alone and being housebound were perceived as major causes of social isolation and loneliness. Wenger & Burholt (2004) found those who were neither isolated nor lonely were all married throughout the twenty year study, with none living alone and most being married men with children living nearby. Pinquart (2003) also found adults living with a partner reported lower levels of loneliness than those living alone.

Gender differences and relationships

Findings on gender differences in levels of loneliness in those living alone are mixed. Pinquart (2003) found men living alone were more lonely than women living alone, with divorced and never-married men reporting the highest levels of loneliness, reflecting findings from many of the earlier studies previously discussed, with various hypotheses put forward to explain this. However, this review found being female and living alone was also found to be associated with loneliness. Victor et al’s (2005) study found a relationship between loneliness, being female and living alone, but no association with levels of social contact or proximity to children, friends and family. They suggest the quality of relationships with others is the causative factor rather than extent or number of contacts. Victor et al distinguish being alone, living alone and social isolation from each other, arguing some commonalities between concepts with unclear overlaps, and the need not to use the terms interchangeably. In Victor et al’s study participants were asked to rate their loneliness levels now as compared to ten years earlier, which they admit is problematic due to response shift. The authors argue self report measures are simple to use, but that such simplicity can also be a weakness since they presume a common understanding of the concept of loneliness by participants when the nature and meaning of the concept is likely to diverge between different people and over time. They discuss how loneliness may be seen as stigmatising by participants in damaging an individual’s identity, and they may therefore be reluctant to disclose these feelings, allowing only the publicly declared prevalence of loneliness to be captured rather than its felt experience. Victor et al used a derivative measure (UCLA) which underwent psychometric testing of its validity and reliability and has been used with older people. However, they demonstrate cultural specificity and rely on indirect questions of social engagement, consequently making assumptions about the definition and meaning of loneliness.

Impact of others

Contact with others was found to make a significant difference to loneliness in some studies. Pinquart (2003) found contacts with adult children, siblings, friends and neighbours were more likely to reduce loneliness in unmarried (living alone) than married adults (living with spouse). Childless unmarried adults benefited from contact with siblings and friends. However, because most never-married older adults have not had children, differences in loneliness could not be exclusively explained by differences in contact with offspring. Correlational data also limits the extent to which conclusions can be drawn from the findings of this study.

Integration into a community was a significant factor in preventing loneliness in some studies. Scharf & de Jong-Gierveld (2008) found integration into the community was protective of loneliness with quality of residential neighbourhood being important. Network type had a significant influence on loneliness with smaller networks associated with higher loneliness. It may be that social support reduces loneliness, which may explain Schnittker's (2007) contradictory findings which suggest loneliness tends to decline with age. This was found to be associated with increases in social support, but both of these changes occurred despite a growing risk for reporting no friends or confidants as well as the increased likelihood of living alone. Schnittker found age-related changes in well-being reflected the kinds of roles and environments that age groups found themselves in. However older people are still more vulnerable to social isolation and loneliness because they are more likely to live alone and have lost roles once vital to social integration.

Different coping strategies were identified, including finding ways to be among others and focusing on daily tasks. Cattan et al's (2003) study was limited to community-dwelling individuals in Northern England and only limited numbers of ethnic minority individuals were included, hence generalising to other populations would be problematic. Although the authors state quantitative measures were also used, they were not described, no quantitative results or statistical measures were presented or discussed. The authors did not fully demonstrate reflexivity – they did not discuss their impact on participants, apart from stating participants only discussed loneliness in terms of others rather than themselves, which they hypothesised to be due to the stigma of loneliness being seen as a social failure.

Widowhood

As reported in earlier studies, Scharf & de Jong (2008) found more individuals were widowed in the 75+ age group and were living alone. Their study was a large scale survey comparing two countries (UK and The Netherlands) with the English data drawing on a survey of ageing in socially deprived areas. They found UK participants were severely lonely more than The Netherlands participants – however the UK participants lived in more deprived areas. Using data from participants living in deprived areas limits the generalisability of the findings to the older population of UK as a whole. The total explained variance was higher in the England deprived areas, suggesting neighbourhood differences may be more important in explaining variations in loneliness scores in England than The Netherlands.

Cognitive difficulties

Holmen et al (2000) found “non-demented” elderly participants reported being lonely significantly less than “demented” participants, but there were no differences in the emotional experience of loneliness. Experienced loneliness involves both emotional loneliness and social isolation (Weiss, 1987). Holmen et al suggest experienced loneliness is therefore an overall concept, including both emotional and social loneliness, objective and subjective. They suggest that social loneliness corresponds more to the absence of a meaningful friendship.

The authors found that social loneliness was more common in participants with dementia and increased with reduced cognitive functioning, while emotional loneliness decreased. Participants living alone experienced more emotional and social loneliness than those living with others, while living with others and in one’s own apartment reduced feelings of loneliness. The authors acknowledge methodological difficulties in assessing loneliness in people with dementia, and questions arise as to whether participants with severe dementia understood the questions being asked. They do state it was difficult for those with moderate to severe dementia to understand the questions. The paper does not come across well as it refers to people with dementia as ‘demented’, which sounds derogatory, and is also unclear in parts, possibly due to translation from Swedish.

So, in these studies of loneliness it seems that the majority do find that those who live alone are more vulnerable to loneliness than those who live with others, although the research suggests a number of variables influence this including: contact with others, the extent of social integration and embeddedness into a community, whether housebound or not, gender, and cognitive functioning.

Well-being, Quality of Life & Self-Esteem

Seven articles (1, 2, 5, 8, 9, 10, 14) used quality of life, well-being or self-esteem as outcome measures. Two were Australian studies, one by Qu and Weston (2003) (1) comparing older with younger respondents in terms of various self-assessed aspects of quality of life (financial wellbeing, adequacy of housing for current need, self-assessed health measures, sense of loneliness and satisfaction with life as a whole). Walker & Hiller's qualitative study (2007) (5) explored how older women living alone perceived the social and physical dimensions of their neighbourhoods. Michael et al (2001) (8) investigated living arrangements, social integration and change in functional health status in older women in USA. In the UK, Baldock & Hadlow (2002) (10) explored the differences found between users and providers of healthcare, and their conceptions of an acceptable quality of life, while Bowling et al (2003) (14) explored older people's definitions of and priorities for a good quality of life. Two Swedish Studies (2 & 9) investigated quality of life in older people living at home: Hellstrom, Persson & Hallberg (2004) (2) compared individuals receiving help with those not receiving help in terms of QoL, while Hellstrom & Hallberg (2001)

(9) investigated the perspectives of elderly people receiving home help on health, care and QoL.

Design

Five studies used quantitative methodology (8, 1, 2,9,14), all of which were cross-sectional survey designs except Michael et al (2001) and Bowling et al (2003) (8 and 14) which were longitudinal studies. Michael et al (2001) (8) used data at two points in time over four years with a large sample size, Bowling et al (2003) (14) collected data at four intervals over 12 months. One used census data with interviews (Qu & Weston, 2003) (1); two used postal questionnaires (Hellstrom et al., 2004, and Hellstrom & Hallberg, 2001) (2, 9), and two were qualitative designs (Walker & Hiller, 2007, and Baldock & Hadlow, 2002) (5 and 10).

General Findings

Some studies found living alone had a negative impact on well-being. Qu & Weston (2003) found older women living alone were more likely to say their physical health interfered with their ability to undertake everyday activities, and viewed their financial position less positively than those living with others. Hellstrom et al (2004) found being older, female and living alone resulted in increased inability to remain alone at home and lower QoL among those receiving help, and Hellstrom & Hallberg (2001) found living alone and the ability to be alone were significantly associated with low QoL. However Michael et al

(2001) found women living alone had a lower risk of decline in mental health and vitality compared to those living with a spouse and were more likely to improve in mental health. This directly contradicts most research, which tends to view living alone as a negative experience. One explanation for this may be the quality of the relationships for women living with spouses – if the relationship is difficult or if the women are carers for husbands, then this is likely to have a negative impact on their well-being.

Gender differences

Qu & Weston (2003) found those living alone were more lonely than those living with others, particularly men. The authors hypothesise that the stronger correlation for loneliness in men living alone than women may reflect the fact that women tended to have more social contacts than men. They also found men who lived alone expressed less satisfaction with life than men who lived with others. Michael et al (2001) found women living alone were older than those living with others, more likely to have co-morbid conditions and were more likely to smoke than those living with a spouse. They reported fewer social ties (contact with close friends and relatives) compared to those living with a spouse, but were just as likely to report having a confidant. Contact with friends and relatives and level of social engagement were significantly protective against a decline in mental health amongst women living alone but not those living with a spouse. The authors excluded women who provided care for spouses, and repeated the analysis to address the problem of reverse causation (change in functional status resulting in change in living arrangement) over the four years by excluding those whose living arrangement changed. The authors did not ask why women were living alone, though state this does not reduce the strength of observed association. A possible validity concern may lie in the selective survival of women who completed the follow-up questionnaire. A strength of this study is the prospective design, allowing individual change in health status to be measured. Individual-level health behaviours were controlled for, as were changes in functional health arising through catastrophic medical events. The large scale nature of this study renders the findings more valid than the smaller studies.

Neighbourhood & social integration

Walker & Hiller's (2007) study on women living alone found that trusting and reciprocal relationships with neighbours formed an important part of their broader social support networks. Living in close proximity to services and existing social networks were seen as important. Women living in disadvantaged areas were more conscious of social disconnection in their neighbourhoods and the impact of traffic and pollution on their neighbourhood environment. The authors describe the ethnic composition of participants as 'Australian-born', which does not describe ethnicity, i.e., whether they were of Aborigine or European origin etc thereby reducing transferability since there are clearly cultural differences between groups. The authors demonstrated credibility through maintenance of a log and 'considering feedback' from a 'research project advisory group'. However triangulation and the use of multiple researchers is not explicitly mentioned, neither is reflexivity or researcher bias, and so it cannot be described as fully credible or transferable. One author reviewed ‘certain’ themes with participants in order to check trustworthiness of the findings which suggests this was only partially done. Quotes were included to support their themes, adding credibility to the study.

Identity and Selfhood

Baldock & Hadlow (2002) found differences found between users and providers of healthcare in their conceptions of an acceptable quality of life. The experience of disability and living alone re-ordered the criteria by which people judged their quality of life. The order of positive sources of self-esteem were dominated by ‘inner self’, followed by ‘family’, ‘interests’, ‘others’ and ’health’. Inner emotional and intellectual resources were the dominant source of high self-esteem followed by support from a family member. A strong desire to assert the self was found, with participants’ views of services mediated by their conceptions of self. A minority reported being lonely. The design is confusing, since a series of interviews undertaken in 1977/8 were mentioned suggesting this was a longitudinal study, but then they state two interviews were held six months apart between November 1999 and November 2000. They later clarify this in comparing their own sample with the previous ‘GO’ (Growing Older) sample. The authors state that they checked findings but do not state how, making it difficult to judge its credibility, though themes were checked with interviewees. The study is not transferable due to lack of richness of detail.

Physical Health

Hellstrom et al (2004) found individuals receiving home-care help had significantly lower QoL than those not receiving help. Threats to validity include the fact that many respondents had help from family members in completing the questionnaires, possibly distorting the results. The authors argued the short (8 item) questionnaire was used to avoid overburdening respondents with lengthy scales, stating it strengthens the validity of the study in reflecting overall QoL instead of health-related QoL. Despite English not being the first language of the authors, the article is well written and clear. The sample was age stratified to ensure the oldest old (90+ years) were included. Hellstrom & Hallberg (2001) found those with a range of physical and mental health problems had lower QoL than those without these problems which would be expected. Questions relating to QoL were not taken from a standardised measure, questioning internal validity and the findings of this study. As in Hellstrom’s 2004 study, a selection of items rather than entire QoL measure was used due to fear of reduced response rate, and again family members helped to answer the questions possibly distorting the findings, although the authors discuss this. The impact of poor health on QoL was discussed along with the implications for care of the elderly in terms of the greater longevity of women, social networks and provision of home-care by the state and/or family members. Both Hellstrom’s papers tended to focus on physical well-being rather than psychological well-being limiting the usefulness of the findings for this review.

Bowling et al (2003) found deteriorating health and consequent social handicaps were reported to have led to depression and fears for the future, particularly in those living alone. Good social relationships and good health were seen as important with social relationships most important to those widowed/divorced/separated (who all lived alone). The authors do not state why non-responders refused to participate in the study. There were a wide range of responses from participants regarding the meaning of QoL, reflecting confusion in the wider literature. This is a well written article, and the authors discuss in detail definitions of quality of life, and deconstruct the difficulties with QoL as a construct as multi-level and amorphous. Models of QoL are discussed in terms of their inconsistencies, and differences according to culture. The focus in their study is on how older people themselves define what constitutes QoL and what they believe would improve it. The methodology and results are clearly and comprehensively described. Although the authors state content analysis is not a qualitative methodology they include quotes to describe participants' views' and/or experiences which adds depth to the article, bringing it to life.

In summary, most studies on well-being suggest that as with loneliness, living alone has a negative impact on well-being. Factors discussed which influence this were: gender – although studies differed in whether men or women were more negatively affected by living alone, with one study suggesting women living alone had improved well-being; the importance of social network and deprivation, the need to assert the self, and the impact of poor health on quality of life.

Discussion

From this review of the literature on the well-being of older people living alone, it is difficult to draw precise conclusions. There are multiple factors that influence the well-being of older people and this limits our ability to disentangle these variables. In addition, none of the reported studies were totally free of methodological problems. As discussed, the definition of well-being varies greatly, further compounding the difficulty in drawing accurate conclusions, not only in the measurements used, but also at the conceptual level of investigation. The articles reviewed are heterogeneous in nature, making it difficult to synthesise a conclusion. Each study has its own idiosyncratic strengths and limitations which reflect the methodology chosen.

Cross Sectional versus Longitudinal Studies

The larger scale studies such as Iliffe et al's RCT are strengthened by the rigour of design and sample sizes, but are limited in using cross-sectional data at one point in time. The longitudinal studies such as Wenger & Burholt, overcome this problem but are limited by inconsistencies in measurement. The qualitative studies vary in quality, a strength being the ability to capture real and complex participant experiences.

Instruments used to measure outcomes varied greatly, some using obscure questionnaires, others using well-validated measures. Some studies used simple quantitative assessment, whereas others examined underlying dimensions and possible mechanisms. The Quality Assurance Checklist enabled a comparison to an extent, though the heterogeneity of the articles in terms of concepts and focus limits this.

Definitions

The articles using loneliness as an outcome measure parallel the confusion in the well-being literature, in that social isolation is often used as a proxy for loneliness, and it is assumed those living alone will be isolated and therefore lonely. However most articles did deconstruct the concepts, such as Holmen et al; and Michael et al clarify matters by suggesting living alone is not synonymous with social isolation, but that social isolation may have a more direct impact on functional health status, and perhaps loneliness.

General Findings

Most articles conclude that living alone is associated with increased loneliness, and this increases with age. Social isolation also increases, as does an increase in a number of health and social problems in those living alone. Being housebound, disabled or having physical ill-health was found to add to the problem of social isolation which in turn is associated with loneliness, and also has a negative impact upon well-being. Living with a partner appears to be protective of well-being and loneliness in some studies, although this is dependent upon the quality of the relationship – if one is a carer for a partner, the reverse is seen.

Physical Health & cognitive difficulties

Findings suggest needing home-care and having physical or mental health problems reduces QoL; whilst being housebound results in an increased desire to assert the self. Individuals without dementia report being lonely less than those with dementia, with those living alone experiencing more emotional and social loneliness than those living with others.

Gender Differences

Articles investigating gender differences produce conflicting findings, although they suggest quality rather than quantity of relationships with others is the key factor. Where men are found to have lower well-being, this is hypothesised to be due to having smaller social networks.

Impact of others: neighbourhood and social integration

Findings suggest contact with others outside the home is more important for those living alone than those living with a spouse, which is unsurprising. Integration into a community, social support and network size all appear to influence levels of well-being and loneliness, with larger networks being more protective. Quality of relationships with neighbours and social networks appears to be more important for women living alone. The well-being articles mostly find a negative impact of living alone, particularly in women, though Michael's large-scale study conflicts with this. Again it is likely that the quality of relationships is the mediating factor, though this requires further investigation. Quality of relationships is likely to be an area requiring a qualitative methodology in order to uncover the complexities of individual lives which is often missed in large scale quantitative research.

Other factors to consider – culture, class, ethnicity, education

Most studies, for reasons of rigour, focus on specific populations, but this limits generalisability. The issues of poverty, social class, educational attainment, ethnicity and culture were briefly mentioned, but may greatly influence outcomes. The socio-political point in history in which we are living also impacts upon the opinions, attitudes and lifestyles of study populations and researchers. As discussed in Victor et al's review (2000) much of the research conducted on older people and the links between age, loneliness, well-being and living alone was conducted decades ago, and there is a lack of more recent research on current populations. The increasing numbers of elderly people, particularly women living alone, and projected further increases mean that problems associated with ageing such as dementia, physical health problems and the associated effects of this such as mental health problems, loneliness and isolation, and threats to well-being are likely to increase. Most of the studies reviewed did not fully consider the ethnicity of the study population, and so it is assumed the study groups consisted of each country's indigenous population. Ethnicity is an important variable in the UK population with increasing ethnic diversity and immigration from across the world and would benefit from further consideration in future research. O’Connor & Nazroo (2002) discuss varying responses to mental health problems from different ethnic groups.

The fact that the findings appear paradoxical in parts is likely to reflect the importance of meaningful relationships for older adults living alone. The emotional and practical gains stemming from close meaningful relationships are likely to contribute to well-being, as is perhaps the ability to choose lifestyle and be independent. Where these factors are in place they may negate any negative influence of living alone.

Clinical Implications and further research

Further research is necessary to explore the personal experiences of individuals living alone, also looking at factors that could explain some of the contradictory evidence, for example where a positive association is found between living alone and well-being. Quantitative studies could attempt to disentangle these specific factors, for example whether a reduced sense of wellbeing and/or increased loneliness are due to the experience of living alone, or whether other factors such as duration of time living alone, recent bereavement, personality factors, or other life events are the causative factors, with living alone being an outcome of this. Longitudinal research would need to be undertaken in order to overcome the inherent weaknesses of correlational studies, using for example regression analyses. Longitudinal qualitative studies would add the depth and textural richness necessary in order for researchers and clinicians to better understand the idiographic experiences of people living with dementia, thereby greatly enriching our understanding and enabling clinicians to more fully meet the specific needs of this group of individuals.

This review of research therefore reveals gaps in our understanding of the impact of living alone on the wellbeing of older adults. What it does highlight is the low profile older adults have on the research agenda, which is a concern for those who work clinically with them. The lack of empirical research and consequent clear evidence to indicate if there *is* a negative impact of living alone on wellbeing makes it more difficult for clinicians to meet the needs of older adults living alone since the specific causal factors are poorly understood.

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How older women who live alone with Dementia make sense of their experiences:

An Interpretative Phenomenological Analysis

Thesis submitted for the Degree of Doctor of Clinical Psychology

Prepared for submission to 'Dementia: The international journal of social research and practice'

10,218 words

Abstract

This study investigates the subjective experiences of older women living alone with Alzheimer's disease and/or mixed vascular dementia. Eight women were interviewed about how they managed their identities and coped with day-to-day living, and in the absence of a significant co-resident other who might reflect them back to themselves. Through Interpretative Phenomenological Analysis themes emerged about loss, embodiment, adapting, awareness, safety, relationships, exclusion and loneliness. The women were actively engaged in re-constructing their sense of self, using a variety of coping strategies. Relationships with friends, neighbours and attendance at memory clubs were important. Memory loss had the most significant impact through loss of independence. A search for meaningful relationships was apparent, conflicting with feeling vulnerable and a consequent desire for self protection.

Keywords: Alzheimer's, dementia, living alone, sense of self, women

‘It’s the little things...but they make your life up’ (Emily)

Background

The Alzheimer’s Society (2000) estimates one third of people with dementia live alone. Their report, Home Alone (1994) predicted the number of people with dementia living alone would almost double by 2011 to reach an estimated 245,000. A key recommendation emerging from this report was the need to monitor this group of individuals to provide information for planning services. Webber, Fox & Brunette (1994) found people with dementia who lived alone were more likely to be female, older and poorer. In comparison to people with dementia living with others, they were less likely to use hospital, day centre or nursing home care or see physicians on a regular basis. Dementia not only impacts on daily living, but also undermines individuals' coping resources through its effects on thinking and behaviour, personal, social, occupational functioning and other peoples’ reactions (Kitwood,1993; Preston, Marshall & Bucks, 2007). Social experiences are vital in shaping a person’s subjective experience of life. However, this has been found to be even more so to an individual’s sense of self as they age. According to Coleman (1996) the sense of self is threatened by dementia because it attacks long past as well as recent memories. This is a gradual process and Mills & Coleman (1994) state much can be done to preserve a more coherent sense of self by encouragement to recall their story; however, Coleman suggests a point occurs when a person’s story must be sustained by others. This presents obvious difficulties for people who live alone who may not have someone to do this, rendering them especially vulnerable to erosion of sense of self. People with dementia rely on others to reflect them back to themselves on a day to day basis, and in order to remind them of their past selves. The importance of relationships with others in maintaining personhood has been extensively explored by Kitwood (1997; Kitwood & Bredin, 1992), Cotrell & Schulz (1993), Snyder, (1999) and Harris (2002).

Sibley et al (2002) found participants who lived alone were diagnosed with dementia at an earlier stage than those who lived with others, while Fratiglioni, Wang, Ericsson, Maytan & Winblad (2000) showed unmarried participants who lived alone and who had no friends were at a higher risk of developing dementia. Socially or mentally stimulating activities have been found to protect against dementia (Wang, Karp, Winblad, & Fratiglioni, 2002). van Gelder et al (2006) found marital status may be a stronger predictor than living situation on cognitive decline, while Berkman (2000) and Fratiglioni et al (2000) suggest being single (not married) is associated with a higher risk of dementia than living alone.

Research suggests individuals with dementia use a range of strategies to manage the effects of the illness, with differences between men and women (Billings & Moos, 1981). Pearce, Clare & Pistrang, (2002) studied men with Alzheimer’s disease (AD), and found they were actively involved in managing their self-identity – men relied on their wives for practical and emotional support, with their relationships with their wives being a factor in reappraising their identities in light of the changes they were going through. This leads us to question how women cope with the experience of dementia, and in particular, how women who do not have a partner to rely on for emotional and practical support, manage their self-identity and the experience of dementia. Until recently there has been little focus within the UK on broadly based qualitative research about the lives of older women, particularly that adopting a 'life story' approach.

Sabat, Fath, Moghaddam & Harre's (1999) tripartite conception of selfhood is a social constructionist model, whereby Self 1 is the self of personal identity expressed through the indexical 'I'. It is not reliant on others for its existence, and hence not damaged by dementia (Sabat, 2001). Recent research by Clare, Rowlands, Bruce & Downs (2008) has demonstrated retained awareness of the self in persons with severe dementia. Self 2 comprises the person's attributes, and their beliefs about those attributes, and is divided into the restricted Self 2 - those attributes and beliefs held at any one time, and the unrestricted Self 2 - those attributes and beliefs which are stable throughout the lifespan. Self 3 is the social presentations of selfhood, or personae. This is how self 1 (the individual's point of view of the world) and Self 2, (the person's current attributes and beliefs about them) are presented during social interactions. A person can be a friend, neighbour, spouse, or parent, and have different beliefs associated with each of these social relationships. In this case, as opposed to the case of Self 1, and Self 2, in order for a person to manifest a Self 3, the person needs the cooperation of another person. Sabat et al suggest that it is in the attempts to construct and produce a Self 3 that we may find evidence for assaults on the self-esteem of the person with AD. The individual maintains a worthy public persona (Self 3) by reaffirming their life to others, by maintaining relationships with others, and by referring back to aspects of his or her former personae in an earlier social world, thereby maintaining pride and integrity (Sabat et al., 1999). However, this requires another person who will participate in the construction of Self 3. Without this the person's attributes and beliefs about those attributes cannot be validated. Sabat et al (1999) describe a 'fuzzy boundary' between multiplicities and pathologies of self which are never stable, drawing different distinctions at different times. Hence seeing the person as '*unitas multiplex'*, allows us to manage research into such matters as the predicaments of selfhood facing sufferers of Alzheimer's disease (Sabat et al., 1999, p9).

It is clear from research to date that although studies have been undertaken to explore the personal experiences of individuals with dementia in, for example, care settings, little has been undertaken to explore how individuals who live in the absence of an other manage their identities and cope with dementia. This study therefore seeks to explore how women who live alone with dementia see themselves and how they cope in their day-to-day lives, in the absence of someone a) to reflect their identities back to them, and b) to help them with day-to-day living.

Methods

Design

Interpretative Phenomenological Analysis (IPA) was used as a methodological approach (Smith, 1996). IPA is based on idiographic analysis which means it examines objects of interest in considerable detail, thus requiring relatively small sample sizes. I used IPA as it is designed to enable us to seek to explore how individuals’ make sense of their lived experiences (Smith, 2004). It understands that meanings of participants are social constructions, not objective truths and requires the interviewer to be reflexive, in attending to one’s own personal and professional reactions to the experiences of participants (Smith & Osborn, 2008). IPA is widely used in clinical and health psychology (Reid, Flowers and Larkin, 2005) and is judged to be particularly appropriate for rigorous and in-depth investigations of psychological experience. IPA is concerned with how individuals construe, make sense of, and talk about their experiences, and aims to capture the quality and texture of individuals' experiences and understand the meanings of the experience for them (Willig, 2008).

Participants

Eight women were interviewed (Table 1). Only women with a diagnosis of Alzheimer’s Disease (AD) and/or mixed vascular dementia and AD were recruited. Inclusion criteria were that they lived alone, were proficient in English, willing and able to talk about themselves and give informed consent for participation in the study, and without any major psychiatric problems, apart from possible reactive depression or anxiety as a result of their diagnosis. The Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975) was recorded for all participants. This well known and widely used scale was used to give an indication of the level of overall cognitive functioning at the time of testing, encompassing a 30 point questionnaire which investigates memory, orientation, language, attention and calculation. At the time of referral, of the eight participants recruited, three had scores in the mild range of cognitive impairment (MMSE 20-26) and five were within the moderate to severe range (MMSE 10-19 - see Table 1. below).

Table 1. Participants' Demographic Details

Participant	Age	MMSE score	Marital Status	Previous Occupation	Diagnosis	Previous co-resident
Ruby	87	26/30	Widowed	? Housewife	AD	Husband
Alice	82	24/30	Single	Medical Professional	AD	Mother
Emily	75	17/30	Widowed	? Housewife	AD	Husband
Grace	75	19/30	Divorced	Factory Worker	Multi-infarct dementia	Children
Vera	83	18/30	Widowed	Factory worker	Mixed multi-infarct dementia	Husband
Florence	95	14/30	Widowed	Housewife	AD	Husband
Hilda	79	24/30	Widowed	Housewife (husband in army)	Mild dementia	Husband
Lilly	89	18/30	Widowed	Pharmacy Assistant	AD	Husband

Procedure

I recruited participants from an NHS Older Peoples' Directorate in Birmingham after obtaining NHS ethical approval (Appendix 1) and informing participants' Care Coordinators and GPs of the nature of the research (Appendix 2). I informed participants that their involvement was voluntary, that they had a right to suspend the interview, and I gave them a Participant Information Sheet (Appendix 3). I checked understanding before obtaining informed consent (Appendix 4) using a well-defined procedure developed by Arscott, Dagnan, & Stenfert-Kroese (1998) and consonant with expectations of The Mental Capacity Act (2005). I first met with each participant prior to the research interview to explain the procedure and obtain consent. Following this I invited interviewees to keep a note of their memory problems throughout the week. I offered to telephone them once during the week as a prompt, although most declined this offer. One week later I undertook approximately hour long interviews with each participant using a semi-structured interview guide (Appendix 5) and tape-recorded this interview. The interview gave the women the opportunity to talk about the impact of their memory problems, past and present views of themselves, their relationships with others, coping strategies, and how they manage living alone.

Analysis

The first stage of analysis involved reading and re-reading the transcripts and close line by line coding of the experiential claims, concerns and understandings of each participant – this is phenomenological coding (Larkin, Watts & Clifton, 2006). Making notes by reflecting upon my own processes allowed me to bracket off my preconceptions so they did not contaminate the phenomenological stage (Smith, 2008), and access unconscious assumptions and values which may impact on the conduct of the research (Rolls & Relf, 2006). The second stage (interpretative level of analysis) referred back to core experiential accounts but was not constrained by them – this was a creative process using images, reflection, metaphor and genre. A ‘dialogue’ was created between myself, the coded data and my psychological knowledge about what it might mean for participants to have their concerns (Larkin et al., 2006; Smith, 2004). After making notes on each side of the margins on the transcripts, and noting emerging sub-themes, I compiled a list of emerging themes for each transcript which I then clustered into groups. From these I identified main themes and compiled a table of Master themes from across the group of eight transcripts (Appendix 6). In order to ensure credibility and trustworthiness of thematic accounts, I checked emerging themes with my supervisors and other researchers undertaking IPA research. As noted above, I sought to triangulate the data by asking participants to keep a diary, in addition to verbal interviews. However, only one participant completed the diary, and this data is not presented in this report. Data was triangulated as fellow IPA researchers and supervisors also analysed parts of transcripts. Supervision enabled me to develop ideas and look at the data from different angles. This ensured trustworthiness and transferability were maintained throughout the research process, which I feel can be seen from the rich texture of analysis of these women's narratives (Lincoln & Guba, 1985).

Results and Discussion

I identified four overarching themes from my analysis. These were: 1) Living with a changing sense of self, 2) A fluctuating awareness of memory problems, 3) Seeking sanctuary versus risking danger, and 4) Being with others: connection versus disconnection. I will discuss each in turn, reflect upon the process as appropriate, and shall follow with a conclusion and more detailed account of reflexivity (Appendix 7).

Theme 1. Living with a changing sense of self

Loss of past self

Participants described a number of losses during the course of their lives. For most women who had been married, the death of their husbands was described as their biggest loss:

> 'I came in in the morning with a cup of tea for him and found him gone! that was a bit of a shock - you say daft things though, his arm was hanging down and I said, "what have I done to deserve this?" and daft things, and went back in the kitchen and drank his tea! [laughs]' (Emily) L13

Emily paints a vivid picture of the shock of finding her husband dead in the living room of their flat. This was recounted less than a minute into the interview and the way the story is retold in the irony of drinking his tea illustrates how she uses humour to protect herself from the shock then, and pain now, and also minimises it in her language. Saying it so soon also implies it is very important to her to convey a Self 2 (life long attributes) with being married being a core part of her identity. Humour was used by most participants (particularly Alice, Ruby, Emily) as a way of coping with psychic pain. Hilda initially found the loss of her husband too painful to talk about, though later said:

> '…nobody could replace him…I sometimes sit here and think, I used to/ erm would he have got married again, you know, and somehow I don't think he would either, that's how close we were, you know [pause] I mean when he was really ill, I was ill, suffering with him [coughs] and he was the same' (Hilda) L597

Hilda indicates the closeness of their relationship and devotion they had for each other – it would be a betrayal to marry again, and no one could ever replace him. She coughs as she recalls how ill he was, indicating how much she empathised and identified with him. Most women (Lilly, Vera, Hilda, Florence) who had been bereaved of their husbands appeared in a state of mourning, lamenting their deaths and idealising the past and their roles as wives. In melancholia, the self is swallowed up in an identification with the lost loved one (Freud, 1925). Freud suggested our egos are made up of the leftover traces of abandoned relationships. Lilly spoke of having been heavily reliant on her husband, finding it hard to cope following his death, feeling bitter he abandoned her. I would suggest Lilly has an anxious ambivalent attachment style, whereby she needs 'a rock' to cling to, feeling unable to cope on her own. Such individuals cling to past relationships following bereavement (Bowlby 1973; Murray-Parkes, Stevenson-Hinde & Marris, 1993). Freud argued anger and hatred directed at the dead person are displaced onto the self, resulting in the melancholic need to berate themselves (Freud, 1925; Leader, 2008). Hilda was a carer for her husband, nursing him in the months before his death from cancer, so her role as carer had been removed from her identity. Grace had divorced her husband many years ago, although he was still ‘on hand’ to help her with gardening and DIY. Alice had never married and the central part of her identity was that of professional, thus loss of this role through retirement was the most significant threat to her identity:

> ‘…I was one of the top [medical professional] if you know what I mean, I was on a committee, executive committee, attended meetings in London, responsible for organising this and that, and was quite an important person... I was one of the top people, and as I say, I lectured a lot and was invited to Australia, read papers there and taught in an Australian school for some time, so I was very very keen on my profession.’ (Alice) L259

Alice’s identity as a successful career woman is apparent from the above extract. In recounting this Alice is able to sustain and support her restricted Self 2 - the healthy attributes she believes she had. It is interesting to note her professional role was in the ‘caring profession’ and she described an attachment to her patients, particularly when they spotted her in the street as adults, after treating them forty years earlier as children. Retirement from her professional role results in fewer people who can offer the cooperation for her to construct a Self 3 (Sabat et al., 1999). Someone such as Alice who has taken pride for many years in her professional role, can no longer take pride in this to the same extent as she is not treated with the deference that would signal social recognition of her accomplishments (Sabat et al., 1999), hence the need in her narrative to emphasise her past achievements in order to preserve her self esteem.

Loss of role as mother became apparent in those women with limited contact with their children. Many talked of them being far away and difficult to get to, and I would suggest this cut-off-ness further exacerbated their feelings of loss of role as mother and nurturer, also contributing to feelings of loneliness and social isolation.

Loss of independence through decreased mobility and declining confidence had a huge impact on participants' lives. For example not being able to drive anymore appeared to dramatically reduce participants' social lives and ability to be self reliant:

> '…stopping driving was the worst thing ever/the worst tragedy that's hit me, it really has changed my life yes, and I was surprised, stopping next to my doctor in the car park! And he came over and said "oh I didn't know you were still driving, at your age!"' [94 years] (Florence) L409

The above illustrates how memory problems and age result in loss of independence after Florence's doctor stopped her from driving. She had previously been 'chauffeur' for friends so her role as helper had also been lost, with the role now reversed as she needed to be helped. I was initially surprised at this being described as a tragedy, however, the ability to make their own decisions and look after themselves was hugely important for these women to feel they had some control over their lives and maintain attributes they viewed as important, i.e. relating to Self 2. Vera had lost mobility, meaning she could not garden anymore, leading to frustration, depression and feelings of helplessness. Loss of Vera's cat 10 years earlier had been a significant loss of attachment figure:

> '…I got too fond of him you know, I missed him too much, I wouldn't like to let meself get too fond of one again, especially at my age, I mean I might outlive him and then I'll be sorry' (Vera) L283

I think Vera's mourning for her cat allowed her to mourn for the death of her husband, which was too painful to acknowledge. There is the sense that she was cut off from her emotions and it was difficult for her to get in touch with feelings during the interview. She was the only participant diagnosed with 'reactive depression', although I would say Lilly also had some depressive schemas. I felt that she felt she could not influence the outcome of threatening events, which Seligman's (1975) theory of learned helplessness states is crucial in the psychogenesis of depression. Memory lapses and blanks were more frequent with Vera than other participants. Whilst this might be interpreted as being a simple consequence of dementia, perhaps it indicates the role of emotional responses in exacerbating progression and impact of dementia (Kitwood,1993), as contrasted with participants who used a more active style. Here Lilly talks about mourning the loss of memory:

> '…my memory is not good, no, erm I had a wonderful memory at one time, you know when I was working you know at [pharmacy] I had no problems at all, and then it just come on…' (Lilly) L408

Again, loss is the theme here, hence the importance of Lilly emphasising the good memory she used to have.

Much of the above appears to be about erosion of Self 2, with some participants less able to build and re-build Self 3, due to lack of contact with husbands, children and friends who knew their Self 2 attributes and could have reflected them back.

Living with an unwanted self

The embodied self can be seen to be in a state of flux as the women age physically and psychologically. Physical disintegration of the body was a factor voiced mostly in terms of the impact this had upon the participants' mobility and consequent freedom and independence. Structural disintegration of the ageing body was a part of the felt and seen experience of living with a changing sense of self. If there was a disparity between chronological age and the felt experience of ageing, this created a conflict, as in Emily, who talked of her body still feeling young, even with a 'lopsided' breast. Kontos (2004) argues selfhood persists even with severe dementia, because it is an embodied dimension of human existence. Participants interacted meaningfully with the world through their embodied way of 'being-in-the-world'. Many had physical ailments which impacted upon their lives, and seemed to hold a more prominent position in their conscious awareness than psychological pain or neurological ageing. Emily's removed breast (due to cancer), Hilda's diabetes, and Alice's partial deafness were more readily brought to our interviews than the more painful and apparently suppressed threat of losing their minds:

> '…well I do try and wear three-quarter-length things because of all these marks, cos I've got them all over my legs as you can see [shows me her legs]' (Florence) L810

Here Florence indicates that even at 95 years old, she is concerned about the physical appearance of her ageing body by trying to cover up her damaged skin. However she is happy to show me, suggesting she sees me as a health professional who knows about medical conditions, or as someone who may be able to help her – this seems to be more acceptable than discussing memory problems.

Alongside the physical disintegration of the seen body, was the physical disintegration of the unseen body - the ageing mind and brain cells of dementia. Here the dichotomously constructed concepts of mind and body merge and overlap as participants sought to understand the lived experience of having dementia:

> '…so I know all about acetylcholine and cholinesterase! [laughs] which I gather I am lacking in my brain!/cos they think its something to do with acetylcholine?/ yes they've gone a bit peculiar [both laugh] so I'm not daft as far as anatomical brain things are!' (Alice) L294

Alice uses her medical knowledge to try to understand what is happening to her, whilst letting me know memory decline does not mean she is stupid. Loss of intelligence would be a major threat to Alice's identity, so the laughing protects her from the pain of awareness and of loss of role from doctor to patient. It was important for her to let me know she is not ignorant and hence still in role of doctor, limiting her awareness of what this means by joking and using the word 'peculiar'. Alice took *a 'huge regime of medication'* whilst watching 'the Olympic games' L422 – the irony of watching healthy bodies in sport was juxtaposed against her own fragmenting body which could not exist without having to live according to a strict regime of medication. Hughes (2001) and Aquilina & Hughes (2006) argue we are situated-embodied-agents – we are persons because we are situated (in a variety of contexts), embodied, and agentive (we do things).

Alice seemed to feel an affinity with me during the interview - perhaps as a student and health professional I reminded her of herself and the halcyon days of her youth as a student and young professional, travelling to conferences and writing papers (I describe this in more detail in the reflexivity section in appendix). Alice thus seemed to be showing a great sense of loss of her youth and grief about her impending loss of mind.

Adapting to a new self

Participants adapted to a changing self through various routes. Some used acceptance – reducing expectations or seeing themselves as having had a good life (Florence, Hilda, Ruby, Grace), others saw themselves as fighting against adversity by using various coping mechanisms (Alice, Hilda, Grace); some felt the self would continue through others after their death through passing on their values (Ruby), skills (Grace) or genes (Florence, Emily). Participants talked of how they fought against decline by 'sheer willpower' (Hilda). Alice talked of people with strong characters, and felt 'well in control' and that she could cope with every circumstance that cropped up. Strength in fighting against adversity and 'putting on a brave face' were seen in all participants to differing extents - an aspect of Self 2 they wanted to convey. Most participants talked of coping – *'but I'm still coping, you know'* (Ruby) L621, and 'keeping going'. Hilda described coping with forgetting:

> 'I always think "what day is it today?" [laughs] because every day is the same! So I try to make it different and I get dressed and go out!' (Hilda) L371

The above illustrates participants actively involved in managing threats to their identities through various strategies. Some used religion or had values they had lived their lives by, which they fell back on in times of stress as sources of comfort (Grace, Ruby):

> '…oh yes, they come sometimes [neighbours to help], yes I don't really have no problem in that direction you know, I have to say really, God was good and kind to me because I see people with problems…' (Grace) L147

Grace saw herself as lucky because she could always find help, and felt God guided her through her life, whilst being one of many participants who used downward comparison to appreciate the life she has. The influence of cultural factors should be considered when trying to understand the subjective experiences of heterogeneous groups of people (Downs, 2000). As Grace emigrated here from Jamaica, her attitude to life is flavoured by her cultural background – her expectations from life, in terms of material matters, were not great as compared to some participants, and I wonder how much culture has influenced the person she is:

> 'I just felt as if, time and all is sit down and rest myself [both laugh] so I don't really bother now, yeah and my memory is bad for putting down something and I can't find it, so when I put down anything now, I don't even write it down, I say "well I'll find it sometime!", I say, "I've got too much junk in the house anyway!" [both laugh] I have to laugh, but would worry some people, don't really bother me' (Grace) L664

Here Grace describes having led a long life and wanting to rest. If she can't find something she does not bother to hunt for it, but accepts it thinking it may turn up later, if it doesn't, she rationalises losing it by rendering it unimportant. This is an active coping mechanism emerging from a solid sense of who she is and a lack of anxiety about the unknown. Her openness to what lies ahead may indicate a secure childhood attachment as she seems to have great trust in herself and others (Bowlby, 1973). Her belief in God takes the pressure off worrying about existential issues, enabling her to fully live in the present without undue anxiety.

One way of dealing with the threat of loss of identity, and future death was to have a sense of continuity of the self through others or generativity (an investment in benefiting the next generation) (Erikson,1963). Participants talked of passing on values or skills to others - Grace passing on her dressmaking skills and sewing machine to her daughter, Ruby talked of the transmission of values inherited from her grandmother and passed on to her children, helping them cope with identity changes and losses:

> ‘ I always try to see the best in people you know…well everybody’s got their little dark spots, but I try to see the best in people…well I suppose its more or less second nature, the way I was brought up, I can’t remember my mother actually saying it to me, but I think she was much the same and my grandma, they always had a nice attitude to people…I think my children are much the same as well’ (Ruby) L709

Ruby lived her life by her core values, and I suspect this helped her cope with dementia. Highly generative adults reconstruct the past and anticipate the future as variations on a prototypical commitment story. One factor is being sensitized to the suffering of others at an early age (McAdams,1998). Alice (the only participant without children) had made her Will and decided who she wanted to inherit her money. She talked of wanting to control her funds, perhaps symbolising her fight against diminishing control and eventual death, and also in seeking to live on though through her nieces, nephews and ex-patients:

> '…a woman came over and said "Oh Miss X, how lovely to see you!", and this happens a lot, and I've been retired for twenty years for heavens sake! So it really, I mean it's very heartwarming when people do that/ "and Peter's 41 now" I mean I remember him when he was a little boy!' (Alice) L744

This illustrates the importance Alice invests in being remembered by her ex-patients – knowing she made a significant positive impact upon thousands of children though her professional role means she will always be remembered by them. As an ex-academic she also wanted to be remembered through participating in my research. The prospect of having her words published meant Alice would live on after her death. Being engaged in this research also meant she could maintain the restricted Self 2 (attributes held at a point in time – for her past job role) and beliefs about the self, and Self 3 – the presented self or persona (Sabat et al., 1999). Sabat (2001) illustrated in a case study, how a participant perceived himself to be a co-researcher in the study rather than an object of research. I think Alice managed the threat to her identity of switching role from doctor to patient by identifying with the aspect of me as health professional, seeing herself as helping me as a fellow academic, thereby raising her status from participant to co-researcher.

Theme 2. A fluctuating awareness of memory problems

Living with a declining memory

Participants used various coping mechanisms such as writing 'to do' lists, writing on calendars, getting friends and relatives to prompt them by phoning daily, humour, and fighting against the decline by learning memory improvement strategies such as playing word games through attending memory clubs. Participants spoke of the importance of these strategies and the camaraderie of being with others at the memory club. Perhaps people with memory problems feel validated by others with the same difficulties as still being valued human beings. Some participants took active control of their memory problems, used strategies such as humour to cope, and fought against the decline thereby protecting their self-esteem:

> ‘…it’s not too bad, obviously when I go shopping I have to make a little shopping list, or I’ll come back with lots of stuff I didn’t really want and that that I needed most I wouldn’t have […]I make a note, and when I’m travelling I’ve always got a list, so if I do have to change trains, I’ve got where I’ve got to change and how long for and things like that, erm [laughs] the one daughter says, “as long as mum’s got her list, it doesn’t matter if its that long [shows with hands small distance] or that long [long distance with hands], she’s happy” [laughs]’ (Ruby) L501

This illustrates how Ruby takes control of her dementia by minimising its impact, accepting she makes mistakes, making light of them by laughing. She uses strategies to ensure dementia does not limit her freedom which reassures her she can still accomplish complex tasks such as changing trains, enabling her to lead a more active and fulfilling life. An important part of her identity is to be seen as coping and strong, as she led rambling groups for 11 years, prior to diminished mobility due to severe arthritis. She uses her daughter’s talk to validate her ability to cope, and it also tells us something of the quality of their relationship – her daughter is supportive but feels her mother can cope with complex circumstances, perhaps an indication of the old restricted Self 2 being continued in the current restricted self 2, and the unrestricted self 2 is still there.

Many participants were in the midst of a struggle in becoming aware of their memory problems and then heroically fighting against the decline, whilst also being aware of a sense of futility - feeling childish and stupid for not being able to do simple things:

> ‘it’s very peculiar, you can’t/ this is what is worrying me that I am definitely losing my memory, and I try, I can read the newspaper, the pieces I want to read, but I’ve found a book, and I thought I’m going to try and read some of that, to see if I can remember what it’s about, so far, I haven’t got very far, but I’m reading the words, it sounds a bit daft, I know the words but I’ve got to read them/and I go over the road and I say to John when he comes home, “what’s so and so John”, and he’ll say, “Oh mother” and then he’ll sort me out, but it’s silly things that I can’t remember, but they make your life up, you know, and I mean you can’t just forget the little things…’ (Emily) L653

This is a poignant account of Emily’s fight against memory decline - she knows she is losing her memory and is puzzled by its impact. She starts by saying she can’t do things she used to, but blocks herself and talks of the worry of decline. She wants to battle against decline by training her memory through reading, but it is a difficult and slow process. She indicates a struggle to understand the words she is reading and feels stupid because of this. She then goes on to say her son helps her, both using humour to cope with the painful awareness of her memory decline. The narrative suggests a role reversal in him helping her, and her feeling small because of this. She indicates frustration at forgetting ‘the little things’, which may be little to other people, but is hugely significant to her. ‘Fighting it’ appears to be a common phenomena in individuals coping with Alzheimer's disease, as also found by Clare (2002).

Shame about forgetting was experienced by several participants, resulting in a desire to cover-up from others in order to protect their self-esteem:

> '…one day, I *completely* forgot about it! And when I came down, the phone was going, she said, "didn't you want a dinner today?" and I said, "oh yes I've had one", she said, "who've you had it off?", so I said, "I've been over the road!" but I said "I'm ever so sorry but I forgot!", she said, "well would you like it?", I said, "yes please", and he brought it back for me, they are ever such nice men [laughs] I felt ever such a fool…'(Emily) L713

Feeling stupid about forgetting led to Emily attempting to cover it up, but she was then exposed when probed, so reluctantly admitted it. She felt infantilised – like a little girl admitting she had been naughty and had done something wrong, but then felt grateful they did not chastise her, bringing her dinner back. Her vulnerability is apparent – in forgetting when she had eaten and needing her lunch, and ashamed of being exposed as a fool and liar, a humiliating event and also to relive. Shame in forgetting in persons with dementia has also been discussed by Cheston (2005). This story illustrates the importance of others in helping participants to process 'mistakes', and their resultant self-evaluations. It was painful enough for Emily to realise she had made a mistake and try to cover up, but if the response had been to ridicule her, this would have increased the threat to her personal identity, perhaps leading to further retreats into the self and distancing from others to avoid further humiliation and exposure of the decline. Unsurprisingly Keady and Nolan (1995a; 1995b) also found individuals with AD try to cover up forgetting. This illustrates the importance of others in Sabat et al's

Self 3 (self reflected back from others) and how vulnerable it is to damage from others.

Dementia as loss of control of the mind

Fear of losing control of the mind was experienced by most participants though only explicitly mentioned by some:

> '…dementia is a very emotive word *anyhow*, erm, you feel that you haven't got control of your mental processes, and for someone who's highly trained, this is a *shock*, and you wonder what is going to *happen!*, and you are looking into the future, and particularly with my dear friend who is in this home […] that was the chief *physiotherapist*! With a *huge* staff at [hospital] to see what has happened to her, it really sort of worried me as you can imagine, and I was wondering whether I was going to lose my reason' (Alice) L344

Alice dives in to talk about dementia (the only participant who used the terminology), expressing her fear of losing her mind. She uses the second person to distance herself from the pain of it actually being something she has as opposed to one of her (ex)-colleagues. This is particularly painful for someone like her, as she describes herself as 'highly trained', suggesting loss of mind is a particularly severe threat to her identity - as a professional, childless woman who had never married, her intellect was central to her identity. She identifies with her friend who has dementia as a fellow professional, and indicates looking at her is like looking into her own future – losing her 'reason' is like losing her whole self.

Denial versus despair

A major source of conflict surrounded admission of memory problems and/or dementia to themselves, and the desire to defend against acknowledging this, as a way of coping. Most participants gave reasons other than dementia for forgetting, often blaming relatives, for getting, for example, hospital appointment dates wrong in Grace's case, or other health problems, such as mishearing:

> '…I think it exacerbates any problems that you may have/you see, if I don't remember something, which is what my dementia is all about isn't it, it may be that I haven't heard properly, and if I say, "would you repeat that?" people will think/ there are two aspects of looking at that, either she's dotty because she's got dementia, or she hasn't heard, and often *I* feel it's because I haven't heard.' (Alice) L121

Here Alice minimises the severity of dementia by emphasising the extent of her deafness because that is less of a threat to her identity. Her concern is about being misunderstood and categorised as something she is not. McAdams, (1998) suggests defense mechanisms help assure that presentations of the self to an audience through a lifestory appear in a socially appropriate and self-serving manner; Freud (1923) argued they protect us from knowing the unbearable parts of ourselves. Certainly, participants seemed to move between the poles of denial of problems to acknowledgement, then shame and despair at the realisation of this, which seemed to occur when coping mechanisms broke down:

> '…unless it was written down and they didn't keep reminding me, I think it would just disappear…well if I had completely forgotten and they hadn't reminded me, I would get all tightened up you know [makes twisting movement by stomach] that I'd made a mistake/yes I'd feel stupid, I get all keyed up inside and I could shout at everybody! [laughs sadly] (Lilly) L514

Above Lilly shows her vulnerability in needing reminding, and her description of her memory makes it sound like a ‘black hole’ where things just disappear. The twisting movements suggest difficulty in naming the emotion, and her judgement of herself as making a mistake and resultant feelings of stupidity and frustration. She then laughs to hide her shame and feelings of helplessness at her inability to remember. This mixture of emotions was a common response to forgetting, though most used denial more actively, with only the occasional seepage when awareness was brought to the surface due to mishaps or ‘mistakes’. Oyebode, Motala, Hardy & Oliver (2009) also found minimisation and excuses other than memory loss to be common coping strategies.

The preceding quotes make for painful reading and I am reminded of some of my feelings as I left each woman’s house - sadness, despair, emptiness but also admiration at their strength, resilience and capacity to enjoy life whilst coping with such an insidious disease.

Theme 3. Seeking sanctuary versus risking danger

Staying close to home to feel safe

Although some women were prevented from venturing far from their homes due to obvious physical limitations (Florence), others talked of other reasons for not wanting to travel far from home (Emily, Ruby, Grace).

> ‘…that’s what I’m frightened about that I might go somewhere and then you can’t get back – I know it sounds a bit stupid like/like you see on films, but I don’t want to be like that’ (Emily) L925

Here Emily seems to express loss of confidence due to the threat and impact of a diminishing memory; however most participants (Grace, Hilda and Ruby) found it hard to admit this explicitly, perhaps as a defence against the fear of death and annihilation, pride, and not wanting to appear weak and helpless.

The accounts suggest a need to retreat to a place of safety (the home), which could also represent a retreat into the self. This need may arise from a perceived threat to the self which is both internal and external - the internal threat is the experience of forgetting (near past events, for example where something has been put, what happened yesterday), combined with the external threat emerging as a result of this. Klein (1946) talked of the house being symbolic of the mind, the places where we cope with unacceptable ideas are divided off and can be represented by different levels or rooms. This is illustrated by Grace who talked of being worried about being taken advantage of:

> '…and I was mad at her really but then I know now she wouldn't do that again, you see because, she means well but you see it's the danger people who don't know and they might go around and they come and break into my house and I see that one and I say, "this was the one!" - they are going to say, "Well your memory is no good"' (Grace) L181

Here Grace describes how she felt when her daughter told her her memory was bad in front of others - feeling vulnerable about people outside of her family knowing she had memory problems in case they exploited her. This illustrates how someone with dementia can feel threatened by being seen as less credible as a witness than someone without memory problems. Also the breaking into the house may symbolise the sense of someone breaking into her mind – of people having access to thoughts she is not aware of and of her being unable to control who has access and who has not. An underlying fear in all participants' interviews was of losing control, probably rooted in popular ideas of dementia as someone 'losing control' of their mind. Consequently the need for a safe place arises – a safe place can also been thought of as a refuge from worrying about the future and avoiding existential crises. A way of warding off threats to identity may be what Grace does in the following extract where she had forgotten she had put some money away and then found it:

> '…well I said thank God for five minutes! I went down on my knees and said, "thank you father in heaven!" [both laugh] yeah I did, I find one hundred and then go back and find seventy pound, I have to be glad! Yeah but I did glad, I had some bills I needed to pay and I went and pay' (Grace) L601

Grace did not worry about how/why or whether she had forgotten she had put the money away, but believed God had been good to her by putting it where she could find it. Grace was the only participant who explicitly talked of religious beliefs, though many participants, particularly Ruby and Hilda appeared to have a guiding set of principles which they had used throughout their lives in order to make decisions and do 'the right thing' as Ruby explains:

> 'I've always been a fairly good listener, as well even if I don't always agree with their opinions, erm not sort of be bombastic about minor things, perhaps my opinions wouldn't fit in with their lives, or something I don't know [pause] there's an old saying isn't there, "do unto others as you would be done unto"…I try to do that…even if I think inside, "silly old fool!" [both laugh] but I wouldn't dream of saying it/and as I say, a lot of them didn't have the advantages of having an education…' (Ruby) L222

Here Ruby describes how her values and mottos, inherited from her mother and grandmother, are actively used in her relationships with others and perspective on life. I wondered whether, as one’s identities are stripped down, with the layers of past roles and experiences removed through dementia, then the core values become exposed to help or hinder the trajectories of the rest of their lives. Kitwood (1997) talks of how dementia can hold some opportunities for development, particularly as disinhibitions are lost and an underlying self can be shown – perhaps a fundamental Self 2 can thus be more authentically shown as Self 3.

Coping alone

Some participants (but not Alice, Grace or Ruby) talked of finding living alone hard to cope with:

> ‘I just about manage, I won’t do anything that I don’t feel capable of I mean I can manage the few finances that I have, like the mortgage I suppose, cos it isn’t/ yes it is paid for!’ (Lilly) L322

This illustrates how Lilly wants to reassure herself and let others know she can manage, but is aware she cannot cope. She forgets whether she has paid her mortgage or not, leading to more self-doubt about her competence at looking after herself. The struggle to cope then leads to conflicts about whether to move into a nursing home:

> ‘…sometimes I think, “Oh shall I go into a home?”, but I don’t know whether I would settle in a home’ (Lilly) L336

Going into a home was seen as ‘giving-up’, and associated with the loss of freedom that participants had whilst living independently. The ‘not-settling’ refers to conformity of behaviour/experience suggesting a giving up of her personhood (Kitwood,1993).

Ruby suggests her childhood as an only child made it easier for her to cope with living alone, but reveals vulnerability again:

> '…well I never feel really alone, as you can see its quite busy here [looking out the window] I know quite a lot of people, I know a lot by sight and quite a few by name, and I feel living here, I could shout out of the window and yell [laughs] for help if I needed it' (Ruby) L789

Neighbours were mentioned as important in helping participants in practical and emotional ways, also found by Walker & Hiller (2007). Both Alice and Emily had relatives living in adjacent blocks of flats, who they had good relationships with and helped them, and Vera and Florence had carers coming into their homes to help and talked of them as providing companionship. Vera, Ruby, Lilly, Emily, Grace all spoke of feeling they could rely on neighbours if they were in need:

> '…so I need somebody tall, so I called me neighbour and he screw in bulb, he took it away with him and got me a bulb, so he good the one next door there [points to other side of house] they Indian, they very nice people you know, we get on alright, cos sometime they go, "Mrs XXX you want anything or want us to do anything?"…Anyone up there [points around] this lot there, and they'd come! If anything they come and call me sometime as well!'(Grace) L130

Above it can be seen how Grace feels supported by her neighbours for practical support (to fit a light bulb) but also emotional support, in her knowing she could go to them if she needed anything. She associates being nice with being Indian and it may be that her concept of them being 'immigrants together' may have created a bond. Her self esteem was preserved by feeling she could help them if they needed anything and so the relationship felt mutually supportive rather than one-way. Both Grace and Alice described being happy living alone – Grace had managed living alone since her children were young so had no problems, similarly Alice had lived alone since her mother had died and had no problems coping either – *'no, no problems at all'* (Alice) L726. However some spoke of feeling lonely:

> '…I mean I've got my son over there, and people here, but yes, I do feel very lonely, and when you go out, cos I just want to go out, but you've got to come *back* and then sometimes I feel really, really down when I come back' (Emily) L701

Other participants (Lilly, Hilda) also spoke of the importance of getting out of the house to prevent feelings of loneliness. Cattan, Newell, Bond & White (2003) argue the quality of social networks influences negative emotions. Some participants' social relationships did feel unrewarding (Emily), but also the amount of contact could account for feelings of loneliness.

Threat of change

Emily worried about being evicted, which was tied up with anxiety about the possibility of losing her mind, and then being forced to go into a home against her will:

> '…I don't know why, but somebody wants to move me out of here, but I don't want to move, and she [warden] said, "You're up to date with your rent, you're clean, and you're tidy and you are no trouble to anybody, why should you leave?"… but I kept thinking, they think I'm going a bit stupid in my head, and they'll put me in/cos they've put one lady in/ but I don't wanna be in/I don't wanna go in a home, I like it here' (Emily) L909

The previous extract illustrates the conflict between an increasing awareness of a declining memory, and the anticipated impact of this on her housing, which represented a place of safety or sanctuary. The threat of memory loss had real-world practical implications that were more than just a sense of not being able to remember something. It was as though participants had become stigmatised for having memory problems, then perceived as ‘mad’ and a threat to other residents, and so had to be even more ‘well-behaved’ than other residents in order to keep their homes. Housing was a concern for other participants due to worry of not being able to cope with living on their own in the future (Lilly).

Theme 4. Being with others: connection versus disconnection

Need to belong

> ‘…I *love* company, I always have done, you know, that’s why I joined that pensioner’s club on a Thursday, and which is quite nice, cos now with the nice weather coming we have *coach* trips…all over, you know Wales, and all over, beaches, … I always go out every day, or else I think I wouldn’t use my mouth, you know? If you don’t talk to anybody, just to the co-op up there, I don’t/I walk into [nearby shops] [pause] I don’t get stuck in and miserable and morbid and things like that, I don’t do that, that’s not me…’ (Hilda) L225

This illustrates Hilda’s need for contact with others and her desire to belong to guard against the painful feelings she experiences when alone in the house. The ‘miserable and morbid’ indicates her fear of impending death and need to guard against confronting her mortality through contact with others. There is also the experience of *doing things together*, travel and adventure which many of the women had done in their earlier lives. Hilda had lived in many different countries due to being married to a soldier, appearing to feel claustrophobic when inside and alone. Her past identity was tied to being with others. Alice also talked of her need to be with others where she describes her social group:

> ‘…we’ve disbanded from the WI cos we can’t meet anymore, but we call ourselves the ****** and we meet once a month, we’re quite a collection of people, and we take it in turns to organise where we are going for lunch and things, so that’s quite a good casual event and so on, and then I’ve got other friends as well so I’m not short of friends at all’ (Alice) L628

Meeting with like-minded people was important for most participants although only Alice mentioned being a member of a group other than a pensioners/memory club. Alice saw herself as interesting, as she describes the others in the group, and there is a sense of identification and seeking empowerment through collective. The ‘disbanding’ suggests an activist, fighting spirit with a strong internal locus of control.

Alice, Ruby and Hilda’s descriptions of their relationships with others indicated the search for kindred spirits. Hilda described having one close friend who she would share private thoughts with, and Ruby described a brief encounter with a man she met in China following the death of her husband:

> ‘…and people were dancing [↑] ! [both laugh] ballroom dancing! In a paved area of the park and there was about a six lane road to cross, anyway I got straight over there and erm, I was standing there tapping my feet and a man asked me if I danced, and I said “yes”, he said “slow foxtrot?” and I said “yes” and erm, it was lovely, I never saw him again, you know, and he said “I’m here most days and erm, I didn’t ever see him again, anyway it doesn’t matter, I went over there a time or two, it seems funny doesn’t it?’ (Ruby) L 441

Here Ruby describes a desire for a (romantic) relationship with someone likeminded following the loss of her husband - the intensity of which was such that she risked her life to get to him. She describes the need for intimacy that can be achieved through doing (dance) or ‘flow’ (Csiksentmihalyi, 1974), which goes beyond superficial ‘chit-chat’. She also expresses her disappointment the relationship could not develop, then consoles herself by disregarding its importance (and her need). The elderly are generally thought of as asexual, yet both Ruby and Hilda’s descriptions indicate passionate feelings being suppressed when Hilda describes her relationship with her deceased husband - ‘…*God* we were close’ (Hilda) L667 illustrating that alongside her feelings of loss is an intensity and wish for an intimate relationship. Hilda’s desire for meaningful relationships are further illustrated in her comment: ‘…*if I held back and didn’t tell you what I really think, it’s not worth the time is it?*’ L287. This suggests a desire for honesty and wanting to be known, conflicting with the need for superficiality to protect herself - her description of herself as ‘reserved’ reflects a need to want to be known deeply, rather than be simplified and pre-judged as an ‘old woman’. Hilda, Ruby, Alice and Emily mostly clearly indicated a desire to be seen as complex, and with this an internal conflict between wanting to be known versus not wanting to be known, and hence not wanting to be pre-judged or simplified.

Privacy

Although members of various clubs, most participants described their relationships as fairly superficial where members talked about everyday issues, but would not talk about their deeper feelings: *‘… it’s companionship, and we chat and talk, and erm, there are quizzes’* (Lilly) L363. They appeared to seek to

’jolly each other along’, not wanting to face the reality of their declining memories, through a collective need to protect themselves, reminding me of the War years when people did this in order not to think of the possibility of being killed by German bombers. Both Hilda and Emily’s desire to protect their privacy, perhaps indicated a sense of shame and vulnerability about having memory difficulties:

> ‘…well I think that’s how it should be, you don’t want every Tom, Dick and Harry knowing all your/ I’m not that kind of person…I’m reserved I think mmm’ (Hilda) L267

Membership of the memory club appears to be a reluctant admission of failure – of memory decline and fragmentation, which perhaps members sought to protect themselves and each other from worries about future decline and death. Having said this, the women all spoke positively about the memory clubs, and membership was spoken of in ways that indicated they were of vital importance - in reducing their social isolation and connecting with other women who had similar experiences of memory problems, even if problems were not explicitly shared, they were collectively felt. From their discourse I again became aware of a conflict between wanting-to-be-known, alongside the *not*-wanting-to-be-known part of them. The wanting-to-be-known part represented the aspect of the self that sought to regain the self that was lost (attachment to their old selves, husbands) and had consequently died. In the process of mourning parts of the self are regained, and this achievement requires much working through (Steiner, 2003).

Exclusion

Participants talked in different ways of feeling excluded from others and society in general. They described feeling cut-off from their children, largely due to geographical distance, while others had become disconnected due to family disagreements (Emily). Some participants had limited contact with others apart from visits from relatives or carers, and contact at memory/pensioners clubs. Although most had regular contact with at least one of their children (Ruby, Florence, Grace, Emily) or other relatives – mainly sisters (Lilly), niece (Vera) or sister-in-law (Alice); Hilda and Emily had become disconnected from most relatives, and seemed emotionally cut off from most of their children. Some felt their children were too busy to help or spend time with them:

> '…I had nobody to back me up for a start you see, I had to do *everything* myself, I know my daughter, she did try, but she's always busy and I don't like to trouble them, and the other one she has moved to [far away]! You see, that was a big surprise to me, but you see it's their life, what can you do?' (Hilda) L254

Here a sense of abandonment, feeling a burden on others, and resentment about this, and for her daughter moving on with her life and leaving her behind are apparent. Social isolation led to feelings of vulnerability about coping alone, and feeling overwhelmed by this. This feeling was also expressed by Lilly, and to a lesser extent Vera and Emily, though they did receive help from other relatives, protecting them to a degree from feelings of abandonment. Florence described how her neighbour had been put into a nursing home, and no-one had told her:

> '…she won't come back but as I say the flat is still empty and every time I hear a noise, I go out and see if there is anyone there, because they never came and told me you know!/we were quite good friends' (Florence) L721

Florence felt angry her neighbour's family failed to inform her of the move, indicating a feeling of them both being *invisible* as people, as though the impact of the move on their friendship was not important enough to consider. Florence's frustration is apparent, along with her futile attempts to make contact again. Sabat states AD sufferers are often cut off from many activities that define their social worlds, and as a consequence suffer a loss of self-esteem as a result of a lack of opportunities in which aspects of the self can be expressed – i.e, fewer available people who can offer the cooperation required to construct Self 3.

Conclusion

The majority of women in this study were widowed and many mourned the loss of their husbands and past selves. Participants sought to emphasise the unrestricted Self 2 – the stable attributes held across the lifespan, while mourning for the restricted Self 2 (past attributes). However many were actively involved in reappraising who they were and continued to develop their relationships with others - with friends, neighbours and social clubs such as memory clubs forming a focal point for socialisation.

Although memory loss was something most women worried about, its impact in potential loss of independence seemed to have a more significant impact on most of their lives, and appeared to be tied up with ageing and bodily decline - for example in preventing them from going out due to fear of not being able to get home through forgetting the route, or loss of driving licence. All of the women had people in their lives who they had frequent contact with - some were relatives, although friends appeared to take a more prominent role in their lives than family members, perhaps due to the camaraderie of being with others like themselves. Some women were lonely and isolated and craved company but struggled to find like-minded people. A search for meaningful relationships or soul-mates was apparent from the women's talk and a desire to be known deeply rather than be written off as old women. This conflicted with feeling vulnerable and a desire to protect themselves from memory loss, others and possibly death.

Ethical issues

The necessity of forming deep relationships with individuals in order to obtain rich data for qualitative research, and the similarity of this to a therapeutic relationship has been discussed by Lewis (2008) amongst others. It requires a highly developed capacity for emotional engagement in the client's subjective experience (Lewis 2008), with interviews providing a container in which participants can think about hitherto unthinkable aspects of their lives (i.e. the significance of dementia, earlier and future losses and associated pain) and allow them to take shape (Bion, 1959; Leader, 2008). However, in doing this one also renders an individual more vulnerable, as they begin to connect with their own emotional experience - because it is inevitably painful. Within a therapeutic relationship this is contracted into, thought about and processed by therapist and client, and decisions are made about courses of action both within and outside of therapy. It is also contained within a particular setting and timescale with its own rules and boundaries. With lonely individuals this can be difficult to manage, particularly when the relationship is part of a research study where continuing a relationship with a research participant is discouraged. Because these women may be socially isolated and feel lonely and actually not have friends to talk with, they may be vulnerable to seeing the researcher as a friend and then feel let down when the researcher leaves again after one interview. Booth (1998) discusses this dilemma, arguing for continuing relationships after the research has ended for as long as participants feel they require it. This has many implications – for example regarding: dependency of participants on researchers, misunderstandings about the nature of the relationship after research projects have ended, boundaries, and the pressures and ethical dilemmas this may place on researchers who may not be trained, or feel equipped to deal with an ongoing relationship. Having said this, I felt the desire to contact participants – to see how they were, after possibly opening up ‘old wounds’, or bringing things to the surface that they had not previously thought about – this is the effect of forming a deep relationship with an individual in that it affects both parties. There is no simple solution to this dilemma. Perhaps a way of thinking about this would be to consider what qualitative research is and how it is similar to yet different from a therapeutic relationship. This is beyond the scope of this paper, however, the possibility of undertaking long term research with such individuals, that is well-defined may be a way of continuing a relationship with lonely individuals, thereby filling a void or reducing loneliness and giving something back to them. This is briefly discussed in the next section.

Clinical and Research Implications

This research highlights the importance of increasing the visibility of older women living alone, particularly those with cognitive impairments such as dementia. There was a sense of some of these women particularly those without family support, being ‘lost in the system’, with very little outside contact, apart from occasional contact at memory or pensioners’ clubs which were seen as a ‘life-line’.

The experience of shame of having memory problems and the need to cover these up highlights the importance of positive social interactions with others, and, since parts of our identities are constructed from our interactions with others, it also highlights the importance of maintaining *personhood*. This was paradoxically evidenced by participants *coming alive* during the interviews and having the desire and ability to talk with depth, animation and richness about their inner worlds and personal experiences.

This research indicates that the experience of dementia puts additional strains on ageing individuals, which is compounded by the practical and emotional experience of living alone. Ageing, living alone and the experience of dementia can produce barriers to individuals being able to get out of the house and into the community, access resources and cope with day-to-day living. It also makes it more difficult for these individuals to have access to others in order to form meaningful relationships, and hence continue to construct and reappraise their identities. This highlights that it is important for professionals, such as Clinical Psychologists, to engage with marginalized and disempowered individuals such as these women, perhaps to enable them to form connections with others of their generation, through supporting them in forming community groups where they could be encouraged to express themselves creatively and explore their identities, or just *be* with others; and to raise the profile of older people with dementia, thereby raising the public's awareness of the personal experience of dementia.

Further research is needed on the personal experience of dementia, particularly, in light of the expanding ageing population, and women's greater longevity. Further idiographic studies such as this one may help us to build a more comprehensive picture, and hence better understand the experience of living with this complex and widely misunderstood disease. Longitudinal qualitative studies could help us to discover more about how individuals cope with the progression of dementia, thereby enabling us to work better clinically with such individuals. Longer term longitudinal work would also perhaps help us to give something back to lonely individuals, thereby overcoming some of the difficulties in working with lonely individuals and ending relationships. Research teams of clinical psychologists and/or qualitative researchers could maintain research relationships over long timescales, thereby providing a sense of containment, and enabling us to undertake research which would benefit future generations of older adults living alone with dementia.

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Public Domain Briefing

The impact of living alone on older women with Alzheimer's disease and/or Mixed Vascular Dementia

Outline

This research was conducted in part fulfillment of the Doctorate in Clinical Psychology at The University of Birmingham. This research has benefited greatly from the support and guidance of Dr Jan Oyebode at The University of Birmingham, and Dr Adam Cleary. I would like to acknowledge help received from staff at The Older Adult Service of Birmingham and Solihull Mental Health Foundation Trust, and the eight women who participated, without whom this research would not have been conducted.

Background

A rapidly expanding older population is resulting in increased numbers of elderly people, and as a consequence a larger proportion of older people living alone. Women's greater longevity means that a larger proportion of these people are likely to be female. With improved recognition of cognitive disorders such as Alzheimer's disease and vascular dementia, larger numbers of older adults with the disease are now being identified. Alzheimer's disease causes difficulties for individuals because it affects memory, and therefore the ability to cope with day to day living. Although research trials are continually being undertaken to look for ‘anti-dementia’ drugs, there has been limited research on how dementia affects the person. Some research has been undertaken to explore how carers cope with caring for someone with dementia, however little has been undertaken to see how it is for the person with dementia. In recent years there has been an increase in such research, focusing more on how it is for people to live with dementia from their own, personal viewpoint. Some research has focused upon particular groups, such as men (Pearce, Clare & Pistrang, 2002), but little has been conducted upon women, and in particular, women who live alone.

Aims

This study explored the personal experiences of women with Alzheimer’s disease and/or mixed vascular dementia and Alzheimer’s disease who live alone. In particular the study hoped to investigate how women saw themselves in the absence of a significant other to remind them of who they are, of their past lives, and also day to day coping with memory problems.

Method

Eight women who lived alone with dementia were interviewed in their own homes. They were asked to talk about their lives, relationships and coping with memory problems. An analysis was undertaken called Interpretative Phenomenological Analysis (IPA), which involved looking for various themes which seemed to be important for each woman. These themes were then compiled into groups of themes which were common for all the women interviewed.

Results & Discussion

The women were willing and able to talk about their memory problems. The women talked freely and openly about their lives, their pasts, relationships and feelings about the future. They were aware of their problems and sought to understand what was happening to them. Many themes emerged reflecting their personal experiences, with similarities, and differences between the women.

Loss

Most women talked of loss of past selves in terms of a previous identity which may be made up of role such as a wife, or professional role, and loss of mobility and hence independence through ageing and/or physical health problems, and declining memory. They also talked of loss of their husbands who had died, and with them, part of their own past selves.

Adaptation

Participants talked of fighting against decline by using various coping strategies such as writing things down, reducing expectations and accepting their limitations, and using humour, religion or a set of values to help them cope with problems. They also talked about passing on values and skills to the next generation.

Memory problems

The women talked of living with memory problems and a fluctuating awareness of its impact. Sometimes they used denial as a way of coping, at other times they were aware of forgetting things and this was associated with distressing feelings. Sometimes the women felt the need to cover up their memory problems from others due to embarrassment about forgetting. Participants found it easier to think about other problems than memory problems, talking about memory mainly in terms of the practical limitations this had upon their lives, rather than perhaps the more painful aspect of what it feels like to have dementia.

Feeling Safe at Home

Many women talked about wanting to stay close to home, due to loss of confidence and fear of not being able to find their way back again. They also talked of a fear of being exploited by others because of their memory problems and possibly then not being believed because they had memory problems. They expressed a fear of losing control, and therefore wanting to withdraw into themselves to protect themselves.

Coping Alone

Some participants found it hard to cope living alone and also felt lonely, craving the company of others. They talked of supportive relationships with neighbours and friends, though family were only supportive for some women. Several women had become cut off from their families due to geographical distance while others had become estranged due to family disagreements. The women who seemed to cope better with living alone were those who had lived alone for a long time. Some women were worried about being evicted from their homes and being put into nursing homes due to their declining memories.

Relationships with others

The women had a strong desire to connect with others and greatly valued the social groups to which they attended. Mostly these were memory or pensioners clubs, and they felt a sense of camaraderie being with others who they felt were like themselves. The women described wanting meaningful relationships with others and of a desire for a friend or companion who they could talk to in an intimate way, or share personal secrets with, but at the same time wanting to protect their privacy and not expose their personal lives to anyone.

Exclusion

Participants talked of feeling excluded and isolated from others. For example, one very old participant had not been consulted when her friend and neighbour had gone into a nursing home. Some were isolated due to physical mobility problems, others out of fear of the outside world, and some had little contact with others outside of their attendance at memory or pensioners clubs.

Implications and Recommendations

This research highlights the importance of increasing the visibility of older women living alone, particularly those with cognitive impairments such as dementia. There was a sense of some of them being ‘lost in the system’, particularly those without family support, with very little outside contact, apart from occasional contact at memory or pensioners clubs which were seen as a ‘life-line’.

The women talked of the experience of shame of having memory problems and the need to cover up. This highlights the importance of positive social interactions with others, as research by Sabat, Fath, Moghaddam & Harre (1999), and Sabat (2001) suggest, part of our identities are constructed from our interactions with others. It also highlights the importance of *personhood*, as discussed extensively by Kitwood (1997; Kitwood & Bredin, 1992), in them not being written off as having dementia and therefore nothing can be done, but rather of them having a deep awareness of their problems, and a desire for meaningful contact with others, and an ability to do this, with support, sensitivity and respect from others. This is evidenced by participants *coming alive* during our interviews and having a lot to say about their worlds and personal experiences.

In light of the findings of this research, it is hoped professionals and others working with women with dementia will have an increased awareness of their personal experiences and be able to support them to cope and have more meaningful experiences of life.

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Contact Details

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Appendices

Appendix 1

Ethical Approval

Appendix 2

GP Letter

UNIVERSITY OF
BIRMINGHAM

School of Psychology

Soraya Frazer
Clinical Psychologist in Training
University of Birmingham
Department of Clinical Psychology
Edgbaston
Birmingham
B15 2TT

20 March 2008

Dear Dr

Research Study:

Full Title: An investigation into how women with early stage Alzheimer's disease and/or Mixed Vascular Dementia and Alzheimer's disease, who live alone, cope with the effects of the illness and manage their identities.

Short Title: The experiences of women with memory problems who live alone.

I write to inform you that your patient ………….. is involved in the above research study. Involvement is voluntary and s/he has signed a consent form. A copy of the participant information sheet is enclosed.

Please contact myself at the above address or the Department of Clinical Psychology on 0121 414 7124 if you wish to discuss this further.

Many thanks

Yours sincerely

Soraya Frazer
Clinical Psychologist in Training

Encl.

Appendix 3

Participant Information Sheet

UNIVERSITY OF
BIRMINGHAM

School of Psychology

The experiences of women with memory problems who live alone.

Participant Information Sheet

You are invited to take part in a research study. Before you decide whether to take part, it is important for you to understand why the study is being done and what it will involve. Please take time to read the following information carefully. If there is anything that is not clear to you or if you would like more information please ask. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

At the moment we know very little about how women who live alone cope with memory problems in later life. By talking to women with memory problems we hope to better understand how they cope and what they find helps. This information can then be used to help other people with similar problems. The findings of this study will form part of a doctoral thesis for a Doctorate in Clinical Psychology.

Why have I been chosen?

I have approached you as I understand you are attending Mental Health Services in Birmingham and Solihull for help with memory problems. I will also be asking around four to six other women with similar problems to take part in the study.

Do I have to take part?

No, it is up to you to decide whether or not to take part in the study. If you decide to take part you will be asked to keep this information sheet and sign a consent form saying you agree to take part. If you decide to take part you are still free to change your mind and stop at any time, without giving a reason. If you decide to withdraw, or decide not to take part this will not affect the care you receive either now or in the future. If, after the interview you have any concerns about the study, you can contact the person responsible for your care to talk through your concerns – this may be your GP or Care Coordinator

What will happen to me if I take part?

If you decide you might like to take part, the person who gave you this information sheet will pass your details on to me. I will then telephone you to arrange to visit you at home. I will then tell you about the study, give you a form to fill in, and arrange to visit you once more. If you wish I will ring you once during the week to remind you about the form and date of my next visit. I will then visit you at the end of the week at a suitable time, or meet you elsewhere if you prefer. If we meet somewhere other than your home your travel costs will be paid. When I meet with you I will check again with you that you still want to take part. Then I will ask you about your experiences of having memory problems and how you cope with them. The interview will last approximately an hour and will be tape recorded. I shall also inform your GP that you are taking part in this study, and, if you wish me to, I will also inform a close carer or relative.

What do I have to do?

I will ask you to keep a short optional diary during the week before the interview in which you write about:

1. What went well today?
2. What did not go well today?
3. Who did I speak with today?

4. How did I feel today?

It is entirely up to you whether you write anything down or not. I will ring you during the week to see how things are going with writing your diary. I will then meet you at the end of the week for the interview.

What are the possible disadvantages and risks of taking part?

You may feel uncomfortable, embarrassed or upset during the interview. This is entirely normal when people talk about their feelings or experiences. The interviews will be very informal and I shall only ask you to talk about things that you would like to talk about. If you feel uncomfortable about any of the questions you are free to choose not to answer them, or if you feel too upset you can stop the interview at any time. You do not have to give a reason. If I feel you are at risk of harming yourself I may contact your Care Coordinator so that s/he can check that you are ok after the interview has taken place.

What are the possible benefits of taking part?

Many people taking part in similar studies say that they have welcomed the chance to talk in depth about their memory problems and how they affect their lives. We cannot promise the study will help you but the information we get might help improve the future treatment of people with memory problems. We can also put you in touch with support organisations you may find helpful.

What happens when the research study stops?

When the research study has been completed, if you request this, you will be sent a summary of the findings and recommendations.

What if there is a problem?

If you have any complaints about the way you have been dealt with during the study or any possible harm you might suffer, this will be addressed. If you have any complaints, please contact Professor G W Humphreys, Head of School of Psychology, University of Birmingham.

Will my taking part in the study be kept confidential?

Yes. All the information about your participation in this study will be kept in the utmost confidence. Short extracts from interviews or diaries will be used in the final report, however participants' identities will be protected. The interviews and diaries will be transcribed and transcripts kept for five years from the start of the study. You will be able to see the transcribed interviews if you wish. The interview tapes will be kept in a locked filing cabinet at the University of Birmingham, and destroyed at the end of the study in September 2009. Your name and address will be removed from all information so that you cannot be recognised or identified from it.

Contact Details:

If you require any further information, you can contact me at the Clinical Psychology Department, University of Birmingham on (0121) 414 7124

Soraya Frazer
Clinical Psychologist in Training
University of Birmingham

Appendix 4

Consent Form

UNIVERSITY OF
BIRMINGHAM

School of Psychology

CONSENT FORM

Title of Project:

The experiences of women with memory problems who live alone.

Name of Researcher: Soraya Frazer

☐ I confirm that I have read and understand the information sheet dated .... (version ....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐ I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

☐ I understand that relevant sections of any of my medical notes and data collected during the study, may be looked at by responsible individuals from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

☐ I understand my GP will be informed of my involvement in the study, and a close carer, or relative if I wish

☐ I give my consent for the interviews to be audio-taped with possible use of my own words included in the final report as long as my identity is kept anonymous.

☐ I agree to take part in the above study.

Name __________________ Signature___________ Date ___________

Researcher ___________ Signature ___________
Date___________

Name of Person taking part___________ Signature___________

Date___________

consent (if different from research)

Appendix 5

Interview Guide

The experiences of women living alone with memory problems

Interview Guide

Identity

1. How would you describe yourself as a person?
Prompt: what sort of person are you, eg most important characteristics – happy, moody, nervy

2. Has having memory problems made a difference to how you see yourself?
Prompts: if so, how do you see yourself now, as different to before you had memory problems?
How would you say you had changed?
What about compared to before you had memory problems

3. What about the way other people see you?
Prompt: other members of your family? Friends? Has this changed?

4. Do other people realise you are having problems with your memory/remembering things?

5. How does it feel telling other people?

6. What is it like when people notice you are having problems with your memory/remembering things?

7. Do you talk to other people about what is happening to you?
Prompt: who? What do they say? What do they do?

8. If I had met you before you started to have memory problems, how would other people have described you?
Prompt: would they have described you differently to now? (eg personality – changes in, characteristics, likes and dislikes)

9. How do other people act towards you now?
Prompt: how do you feel about this?

10. Are there differences in your relationships with other people since your memory problems started?
Prompts: any other differences in your social life, or life in general?

Living alone and coping

1. What does it mean to you, that you have memory problems?
Prompt: how do you make sense of/understand your memory problems?

2. How much do you think about your memory problems?

3. On a day to day basis, how do you deal with having memory problems?
Prompt: do you have particular strategies for helping you? Ways of coping? (practical, mental)

4. Do you think about the future much?

5. Tell me about the different roles you hold inside and outside of the home? (eg community activities, church, voluntary work – check and explore past roles, eg housewife, mother

6. What roles did others in your life hold? (eg gender roles)

7. Which roles do you hold most strongly?

8. How much have memory problems affected your different roles inside and outside of your family?
Prompt: how do you feel the impact of your memory problems have affected these roles?

9. If I had met you before you started to have memory problems, how would you have described yourself?
Prompt: would you describe yourself differently now? How do you feel about the changes to how you see yourself?

10. Who do you talk to about your memory problems/difficulties?

11. How do you feel about living alone?
Prompt: is it something you chose to do? How long have you lived alone? Would you prefer to live with others? What is difficult? What helps?

12. Who do you rely on to help you if you have problems with your memory or problems with any other aspect of your life? (eg practical, emotional)

Appendix 6.

Paper Trail

Emily

Main Themes	Sub-themes	Transcript line	Quote
Having control over life	Private person	3 321	I like my own private space I don't tell em my business and I don't want to know theirs cos its all private isn't it?
	On my own terms	6 327 474-94	I don't mind mixing downstairs I don't care really, I know I sharn't go there forever I only go down there in the evening if I feel like it….i've had enough of *having* to do things…
	Asserting herself	279 284 294 466-70	I don't want to go on Fridays – well I've already told her I don't want to go there see I want to gradually be my own person again I'm not going there, I'm only going on Fridays to [other day centre]
Wanted new self	Identity as Grandmother	8	I'm a Gran to I don't know how many, I've lost track!
Being accepted for who she is	Not being judged	297-300	They are more my type of person…you just have to be yourself!
Coping	Feeling Lucky	91-7 432	I was very lucky cos they don't normally move you I shall be a bit lopsided the rest of my life, but it don't matter!
	Pride	799 825	Well mine have struggled to get their own homes and that, well hers the dad just bought them homes I've never had any debts
	Making good out of bad	247 257 425 433 583	I've met some of the nicest people in the world through him going there We had a long chat and she even got me some tea If you look for it you can make some fun out of anything I could have been sixteen when it happened or anything couldn't i? Well he died in his own chair, which he would have liked

	Humour	18 102 399 438 607 620	What have I done to deserve this? Pop that in the microwave…I did intend the door to be still on! And there was some rough women in there! Shall I have anything left [both laugh] And I thought well I can keep an eye on him – well where's he going to go! Falling over each other they were!
	Denial	397	Its kind of as if its not happening to you
Vulnerability	Importance of fairness	43	She's fair, there's no nonsense
	Self as needing looking after	53-6	She don't spoil, I mean everyone's treated the same
	Lack of control	63-6	I don't know who we are getting
Low expectations of life	Making the right decision	77 264	But it was the exact right thing I'd do it all over again if I had to
Exclusion	Feeling excluded	307	Then they brought in a crowd of ladies and they all knew each other so they sat at one side
Loss of past self	Loss of husband	13	I lost my husband
	Shock	13-17 603-4	I found him lying…well I came in in the morning with a cup of tea for him and found him gone! …bit of a shock I said "what are you doing all dressed?"
Connection	Importance of 'Meals on wheels' men	713 722	I have a dinner brought in most days, now that makes a difference, I don't have to stop in They are ever such nice men
	Contact with other residents	338-41	Nothing to do with the warden, just ourselves, and I quite like that…I can hear all the news that is going on!
	Support of friends	748 767 789	Sometimes we go out together, she's got a car You're very lucky to have Iris as such a good friend, and I am! She was very good when Ray died
Supportive accommodation	Feeling supported by being in sheltered housing	22 498-505 619-23	I pulled the cord Yes that's something about being in a place like this, you can get some help…when I found my husband had gone…they came and took all the weight off me I pulled the cord in the kitchen and

			they got everything organised
Support from Warden	Attachment and support from warden	38-43	I don’t want anybody else coming in here…she’s so good and I’m used to her and I like her and she’s *fair*!
		436	Joyce [warden] was very good
		465	Joyce rang up for me the other day
		495	I told Joyce and she said, “would you like me to ring them and tell them you don’t want to go?”
		639	But she’s been nurse trained
		687	She rings me in the morning and says its so and so day, and I think, “Oh thanks ever so much!”
		908-919	She’s blooming good to me…”you’re up to date with your rent…your tidy and no trouble to anybody”
Sense of inadequacy	Feeling inferior	753	Well she’s posh that’s the common word for her, but she’s still stayed the same with me
		775	I fell over going up there and I got to her house and said “look at my knees can I come in”
	Feeling disrespected	516	Came one day and said this place was filthy, and it smelt and all the rest of it…I suppose I got upset and they’ve never been since
		526	He tells us the flat smells! Now for a professional to say that to me was terrible!
	Feeling stupid	614	Now I think about it its stupid really cos he wasn’t going to go anywhere!
		724	I felt ever such a fool
Threat of change	Fear of getting another warden	40-42	Especially a man, I don’t want anybody else coming in here, I’m dreading it
		63-6	I don’t know who we are getting
Ageing	Fighting against ageing	448	I know I’m old now, but my legs are still going well!
		452-3	I know as you get older, I don’t feel old and my body is going really fast
Vulnerability	Vulnerability	48	She said, “I was hoping to keep it away from you as long as possible”
		553	I didn’t fight back…but I’m not that type of person!
		688	But I have to ask sometimes what day

			it is
Fear of losing control	Fear	44-54 456-63 604 615 626 916-19	I don’t want to go out by myself…its kind of as if something stopping me…I cant tell you what it is I don’t want to go to [day centre] any more but I can’t tell you why I said to him “I’m not looking at your face!” But I didn’t feel like sitting in here with him I didn’t look I just stopped in here They think I’m going a bit stupid in my head and they’ll put me in, cos they put one lady in but she’d really gone
Fear of Death	Worry about the future	735 933	Well my time might come later on Well if my head goes like, and I don’t know what I’m doing
	Shock	384 650	Oh it was cancer! I can’t remember to be honest, everything is kind of a blank
Shame	Ashamed of how she has to live	526-31 550	He tells us the flat smells…”well you’ve never had to live in a place like this!” Well at least I get it cleaned once a week
Resilience	Putting on a brave face	59-60 31-2 386 393	I’m very upset but I have to be cheerful when she’s around But you, you have to get over it I just got on with it and I forget about it, I forget to tell people You’ve only got half a bra on one side, but erm, I survived it!
Fear of eviction	Dissatisfaction with housing	530 560-5 623-6	“Well you’ve never had to live in a place like this!” but I admit they do smell but that is because where we are its difficult because of the lifts…to get the coffin down

	Accommodation worry	909 916-19 921-31	I don’t know why, but somebody wants to move me out of here, but I don’t want to move They think I’m going a bit stupid in my head and they’ll put me in, cos they put one lady in but she’d really gone I don’t wanna go in a home I like it here
Unwanted past self	Guilt over son	176-87 189 238-44	He’s the one I had put into care He was only supposed to be there a short while I’ll never forget when I left him
Memory problems	Forgetting	33 67 146 470 668-75 674 716	Joyce will be here soon, have you met her? I probably told you this I can’t remember where it is What day is it today? But it’s the silly things…I have to ask Joyce every morning what the date is and think to myself what have I got to do today? But its silly things I can’t remember…but they make your life up you know! I completely forgot about it…she said, “didn’t you want a dinner today?”
Fear of losing her mind	Worry about forgetting	653 677-82 925	Its very peculiar, you cant, this is what is worrying me that I am definitely losing my memory I mean you cant just forget the little things…one day there might be something important and I haven’t remembered it That’s what I’m frightened about that I might go somewhere and then you can’t get back, I know it sounds stupid like
	Acknowledging memory problems	445-6 654-660	Well I just can’t remember the simplest things I am definitely losing my memory
Coping with memory loss	Strategies to help memory	447 656	If I write it down I can I’ve found a book and I’m going to try and read some of it to see if I can remember what its about

		662	And they go and do bingo downstairs and I thought I'd try and do that cos I've got to remember where the numbers are
Coping with anxiety about memory loss	Covering up forgetting	718	And I said, "yes I've had one!"
	Normalising forgetting	85	Time just flies doesn't it and you forget don't you?
Supporting each other	Support from son	166-74	I've got my son over the road…he's a good kid to me
		673	He'll say "Oh mother!" and then he'll sort me out
	Feeling responsible for son	173	I went over there with him, he wouldn't have gone unless I'd have gone
		271	Then when I pass away and his dad's already gone, what happens to him then if he can't cope?
Disconnection	Separation from family by distance	105	They've moved with her husbands job to Australia
		145-7	She's got a cottage down, …I've been there but I can't remember where it is
		149	They are very happy out there
		154	None of them are on the bus route so I can't go
		835	I'm hoping I'll get to see this new baby…I'll get somebody to take me!
	Separated from friends by distance	739	I had a friend when we lived in **** but like everyone else they've moved on
		768	But we are too far away really
		771	I have to go into [city centre] and then get a train out, then walk up these country lanes
		955	You've got to cross such a busy road to get into her little country lane, I hated it!
Rejection	Feeling rejected by children	108-111	I don't know what it is anyway
		138	I haven't even got her number
		158-61	She used to come quite often, I've not seen her since she's been expecting
		509-12	My daughter had got the twins…and my son came…but I never see them now
		571	Rotten! Cos I think moms do their best…I had to fight against a great many odds to help them
		517-9	Said it smelt…I suppose I got upset

		 831-6 881-95	and they’ve never been since But I’m still very hurt about them not coming to see me…I’m hoping I’ll see this new baby This other fella…I don’t know any of the family, I’ve not met the family
Hope for change	Hoping for more contact with children	147	I’m glad they haven’t let go, cos I feel they might come back
Existential loneliness	Loneliness	163-5 320 698-705	I’m very, very lonely Some are I think very lonely and ask the carers to get them in somewhere And do you know, I could have cried I felt so lonely
	Depression	703-5	Cos you’ve got to come back and then sometimes I feel really, really down when I come back
Wanted self	Pride in her children	108 178 193 796-804	She’s erm, got a doctorate Physically he can do anything, he’s marvellous He can do anything over there…cook for himself, I don’t do *anything*! She said “Your children have struggled their own way…and mine aren’t doing nearly as good as yours”
Despair	Disappointment	131-2	I said, “I’d be happy with what you’ve got, you might have another boy and things be not right!”

Grace

Main Themes	Sub-themes	Transcript line	Quote
Acceptance of life	Needing to get along with others	6	Because I am an easy person
		13	All the people get along, I don’t make no trouble with anyone
		24	But we get on alright, I have no problem with them
		250	I have no problems really
		133-136	They Indian, they very, very nice people
		378	I did like the girls and we got on alright
Religion as protection from existential crisis	Being guided by the Bible	31	Well God is good and kind to me that way always
		81	I mean the good book say, train up the child
		105	Yes but I don’t preach the Bible to them
		106-113	When I going to church I drag them along with me so they know the rules
	Believing God is responsible for her life	147	I have to say really, God was good and kind
		154	Really I have no problem, so I have to thank God
		601	Well I said “thank God” for 5 minutes
Reluctant coping with memory decline	Has no problems	154	Yes I really have no problem
	Using humour to protect self	44	You know sometime we have a joke you know
		178	You never think before opening your mouth!
		264	I will never let Evelyn live that down!
		596	I’m going to go back up and have a good look!
	Focus on practicalities of life	602-5	Yeah but I did glad, I had some bills I needed to pay
Coping with living alone	Living alone	577	I been on my own from the children young so I cope alright
Feeling disconnection from others	Separated from children by distance	51-57	But my youngest girl she is in America
		438	The one in Germany is my grand-daughter
		440	I used to see them but since the fare gone up so heavy…
		449	Only if its very important they would come

Control	Being in control	543	I say alright then come!
Pride in achievements as a mother	Feeling she has been a good mother (Method of child-rearing passed down generations)	59-70 74-79 88-97 93-98 59-70 85	I grew up with my grandmother and I know what discipline is like And the child was naughty and she slap him…and he come and slap the mother back! Charlene in America she even worse than me! Oh yes and the trainin what they get from me cos I never let them do anything what is wrong I've had no problem with them really because people are amazed Yes that's how I did grow up, and I grow them up just the same
A conflicted dependence on others	Getting help from neighbours	17 28 46 125 130-6 141-143	My neighbour next door…he's a young chap and if I want anything doin You see these people will do But its good when you really have good neighbours So he went upto the bedroom, when I switched the light on So I need somebody tall, so I call me neighbour Anyone! Anyone up there, this lot there, they'd come!
	Contact with children	416 422 425-433	She buy a house up the road now Every morning she give me a ring My son live near here And my son live near here
	Feels others will help her	39 125-30 141-45	And I say come here and buy me so and so So he went up to the bedroom and when he switched the light on Anyone, anyone up there would help
	Getting help from others	232-247	They are coming to take the cupboards out… I am looking forward to it…them doing it up for me

	Support from ex-husband	535 541 545 549-557	The other day I need have some trees cut down and he came and cut them down He rang me to give me some onions When I sick with me heart problem…he was the first at the door I call him and say Gerry come! and he came and clamp it up and chop down those trees
A conflicted awareness of memory problems	Awareness of memory problems	580-2 620 666 304 309 674	Its only the memory is the worst thing … when I put something down I can't find it I have to sit down to think how I get there you know My memory is bad for putting something down and I can't find it My memory is short memory It's the short memory, not the long Probably if it worse
	Forgetting	586-96 611	It was a £100 and I didn't remember it was there I still can't remember I put it away
	Covering up memory problems	159 699	But I don't tell em! But my doctor don't know anything about me cos I don't tell him anything
	Denying memory problems	581	I wouldn't say it was *that* bad
	Others worse than her	616	Cos I see people forgetful, they don't even know where they are!
	Not wanting to go to doctors	729 733 758	Probably my doctor if he want me he write to me Because I am not in any pain and I'm not sick…why bother your doctor? I never really go to the doctor about me memory
	Blaming daughter for confusion over appointments	218-223 263 265-7	"You is the know-it-all…and you come on the wrong date!" Then Evelyn come and take me and it was the wrong day! I say you have the paper in your hand and you can't even look at the paper!
	Normalising bad memory	226 303	She had the paper so who losing their memory now! There is a lot of young people troubling with this, you know, memory

	Not worrying about forgetting	253-257 614-22 626 637 671	If I remember fine, if I don't, well… Well its not a nice thing, but I don't make it bother me Sometimes I say, better not to remember! I stuck in the house but it really don't bother me It would worry some people but it don't really bother me
	Confusion over being in services	707 725	I wonder how they got it, I wonder if it is the right person, unless Evelyn must have told them? I can't even remember now, but I know my doctor don't know
Feeling vulnerable due to memory problems	Fear of being exploited (Anger at being 'exposed' Not wanting people to know has memory problems Fear of being exploited due to memory problems)	163-167 272-3 281 169, 179 163-167 171-176 181-184	"don't you dare tell me my memory not good when somebody else is ere" She know more about my business than I know about mine! Because when they borrow from me they never give it back! I was mad at her We was not alone, somebody else was 'ere They could come and break in It's the danger…they might say, "well your memory not good"
Looking on the bright side	Seeing things in positive light	669 603	I say, I've got too much junk in the house anyway! I find £100 and then go back and find £70, I have to be glad!
Reducing expectations from life	Not wanting to think	651 664 668 679 688	Instead of burstin my brain I goin nowhere I just felt as if time and all is to sit down and rest myself so I don't really bother now I don't even write it down, I say, well I'll find it sometime! Don't even bother to think cos I'm not going to find it! I don't really think about the future

	Cant be bothered to see friends	640 646 660	We used to see each other, I think we all grow out of it Probably they say since I not going to they, they not coming here I *might* go and see them if I feel like it…but I don't really go very often anymore
	Wanting to stay in and rest	739	When I remember how hard I used to work…I sit and watch television…and amusing myself
	Fear of making mistakes	339	Just in case I get in trouble with peoples clothes you see
	Wanted to stop working	355 364	When it closed down I thought, well I don't have to work anymore! I never bothered to work anymore
	Feeling vulnerable due to ageing	457	Now I'm getting older I hate flying now!
Coping with memory loss	Living in the present	688 690	I don't' really think about the future Every morning I wake as if this is the future
	Letting me know has good long-term memory	309-316	I remember my school days and everything...I can tell you anything what is happening about me past
Loss of Past identity	Sees daughter as how she used to be	320 334	My daughter now is just like I was – she is a dressy person She is a dressmaker
	Skills passed down generations	334-7 341 477	She is a dressmaker So let her have it…so she have all the machines so she sewing My step-mother…she was a dressmaker, that's what caused me to love dresses
	Skill in dressmaking	331	I could make any style in anything
	Pride in past achievements	329 331 342	I used to make my own clothes I could make any style or anything I can't remember having any problems with anything
	How she used to be	319	I used to dress up a lot…but now I don't really bother
	Working in factory	349	Its sewing industry, we used to make…all sorts of things
An unwanted New Self	Less interested in appearance	324 328	Why waste money and they still is good clothes It don't really bother me these things

Wanted but lost past self	Sees self as posh	476	A posh woman, that’s where we get it from
		481	She would make me a new dress, and she would make it very stylish
	Baking	379	I started baking…cos when my daughter got married, I baked a cake
		393	I used to bake a cake...if people wanted I bake for them…it’s a long time I don’t bake any
Fear of death	Fear of travel	462	Now I getting scared and I don’t want to go
		648	Cos if I was to go and see them I would have to sit down and think how to get there
Loss of past identity	Past travel	456	I’ve been over there three times…in America
		458	I went to Brazil once
		465	I been all over and I went back to Jamaica once
Idealised childhood	Disappointment - not as idyllic as past memories	468	It was alright but not the same as when I was growing
Struggling alone	Saving money	384	It was a cheap wedding…I didn’t have to buy
		324	Why waste money and they still is good clothes
		452	Well they ring me! They can afford it!
	Strong will	521	I still wouldn’t have him back
	Struggle	526	I just struggle with the children till they past the worst…i did have it rough

Hilda

Main Themes	Sub-themes	Transcript line	Quote
How appear to others – external self	Doesn't want to show off	3 210-11	Not easy, I could bump myself up It's like showing off isn't it?
Desire to be seen as complex	Identity is hard to reduce down	5 134	That's pretty hard to do Its just the way he was, his whole nature
Need for relationships	Need for acceptance by others	8 702	I've got quite a few friends, so I think somebody likes me the way I am I don't know what you think?
Not wanting to be known to protect self	Relationships at surface level	259-65	I don't know that they are supportive
	Desire for privacy	209-10 218-220 267-9 271	I don't like people to know everything I'm a very private person I don't want every Tom, Dick or Harry knowing all your-I'm not that kind of person I'm reserved
Wanting to be known	Desire to be honest	9-10 12 287	And I don't like pretending - what you see is what you get Why put on a front or pretend? Well if I held back and didn't tell you what I really think its not worth the time is it?
Not wanting to be judged	Desire to be accepted as she is	13	People have to take me the way I am
	Self as fair person	14	I think I am fair
Fear of being hurt/rejected by others	Self as sensitive	21	I'm quite soft you know
	Desire to be treated properly	15 18	If people treat me right, I do the same I can't be nasty or anything like that
	Humility	674 678	I'm not that interesting! What's so interesting about me- I'm only an old housewife now

	Fear of upsetting others	34-7	I'm very careful in what I say…I would never want to hurt her
		45	I've never fallen out with anyone
		58-60	And be diplomatic…I tried to be very careful
		62	Its not what you say, its how you say it
		77	You have to be careful how you do it and be diplomatic
		92	You had to be very careful the way you say things
		96	But you have to be so careful
		102	You have to be soo careful
		137-8	I've never known him to fall out with anybody or have any aggro
Sensitivity to needs of others	Empathy	19	I feel for people
		26-7	If they are in trouble or anything I have to help them
		32	If they are in trouble you know
		604	Such a nice man, he doesn't deserve all this
		615	He used to love his holidays, I'm glad we had lots of holidays
	Caring for others	78	I even helped them do it
		556	I was always there for him
		549	I can't leave him
Perfectionism to protect self-esteem – keeping up appearances	High standards	40	Its not clean enough for me
		80	You know for hygiene reasons
		95	They didn't believe in cleaning you know!
		130	He was always very smart, and very fussy in his own appearance
Need for contact with people - camaraderie to guard against isolation/emptiness	Need to belong	49	I belong to a pensioners club
		203	We go to the pensioners club together
		463	I think it's the people you are with you see, you always travel with the same people
		456	We helped each other, it was very close, very nice, I loved the life
		463	I think it's the people you are with you see

	Desire for company	55 225-7 239-41 246	I do like company yes I love company, always have done, that's why I joined the pensioners club I think I wouldn't use my mouth you know? That's why I joined the pensioners club
	Importance of friends	199 379	I've got one dear friend She phones me every Thursday and says, Its club day!
	Dislike of being alone	241	I don't get stuck in and miserable and morbid
Fear of death	Loneliness	242-3	Miserable and morbid and things like that, I don't do that, that's not me
Past self – wanted self – the boss	Past identity – job role	56 90	I used to be a supervisor I liked my job
Loss of past self	Loss of husband	112 114 117 126-7 316 483 504 562 565 583 593 663 667	Only my husband passing away I can't even talk about it now We had such a good marriage you know He was such a gentleman you know He was in good health before this He loved music…want to see the records? He couldn't dance…he did try for my sake That's the kind of marriage we had you see, very close That's why it hit me, I knew it was happening but there's nothing you can do He was such a good man you know Oh no, nobody could replace him I've got to accept it, that I've lost him God we were close and we, you know had such a nice life
Past wanted/desired self	Self as cherished by husband	121-2 599	"Your mother will always come first with me!" I don't think he would either, that's how close we were
	Desire to be loved by others	121-3 202 382-9	I shall never forget that, that really boosted me up She likes coming here She's determined for me to come
Self reflected through others	Need for people	541 545	I like seeing people, I like company I keep in touch with my friends and

			joined the club
Fear of death	Dislike of emptiness	161 164 168	There’s nothing there you know Nothing at all, I couldn’t live like that There is nothing there
Facing death	Acceptance	149 326-31 638 662 700	Time is a good healer Its life isn’t it? You have to take the bad with the good You know I don’t expect a lot now at my age! I don’t hurt so much now, because its just life, I’ve got to accept it I think I’ve done alright
	Ageing	330 678-84	I feel err, not 100% but at my age who does? I’m only an old housewife now, I should be grateful for what I’ve had
	Life as finite	150 635 642	You’ve got no choice, there is no choice I take each day as it comes and if nothing happens I thank God Well at my age there’s no point thinking of the future is it?
Loneliness and Isolation	Daughter busy	156	My daughter did try but she’s always busy
	Separation from family by geographical distance	157-8 177 183	The other one has moved to **** Its hours and hours on the train you know Usually at Christmas time if they are around here
	Lack of closeness to children and grandchildren	184 192-3	I don’t know if they are round here or not, I don’t know She’s alright, I pop in sometimes and she pops down
	Aloneness	154-55 630	I had nobody to back me up…I had to do everything myself I think well there’s nobody else to deal with these problems
Escapism and avoidance of facing mortality	Desire to be outside and travel	229 233 236-7	We have coach trips All over you know, Wales and all over I always go out every day
	Keeping busy with house	271-5 276	I’ve got enough to do to keep this clean and find a decorator And with the garden again
Fear of unknown	Fear	340-3	Yes that’s what I mean, unless there’s

		 711	something else? I daren't leave it just to chance…touch wood I haven't been in trouble
Coping strategies	Seeing others as worse off	283	I dare say there are lots of people worse off than I am!
	Coping	299 335 373 629 682	I don't do anything different to what I did before You've got to be sensible, and I know I'm not 100% but its life So I try and make it different and get dressed and go out! I've got to deal with it I can cope with what I've got I think
	Normalising memory loss	346-50 438-43	But I put that down to old age! What I am trying to say in German…you are bound to if you don't use it!
	Strategies for coping with memory loss	352 363-6 649-59 707-9	I write everything down now If its important I write it down, like dates No because you see I've learnt, what I do now… I mean if its bills or anything it all goes on the calendar
Memory loss	Forgetting	50 254 371-4 441	Where is it my friend lives? Oh what was it? I always think, what day is it today? If you don't use it it's a struggle
Being strong against adversity	Putting on a brave face	373 627	So I try and make it different and get dressed and go out! Willpower I think!...if everything ticks over
Loss of past/wanted self	Loss of past life	456 460 465 536 621-5 668	We helped each other…it was very close, very nice, I loved the life I loved every place I went to I loved that life, never bored I loved it, I did I've got a passport full of stamps Cos we had such a nice life, I loved the travelling

Table of Themes for Group

Super-ordinate Theme	Participants contributing to this theme	Sub-theme	Participants Contributing to sub-theme	Key Cross references	Indicative Quotes	Notes
1. Living with a changing sense of self	All	Loss of past self	Emily, Hilda, Alice, Florence, Vera, Lilly, Ruby, Vera	Hilda (L56, L90, L112, L465, L562, L565, L593, L597, L583, L667), Emily (L13), Vera (L93, L34), Alice (L259, L740, L738), Florence (L293, L381, L409), Vera (L283), Lilly (L408, L594, L263), Ruby (L777)	'…nobody could replace him…I sometimes sit here and think, I used to/ erm would he have got married again, you know, and somehow I don't think he would either, that's how close we were, you know [pause] I mean when he was really ill, I was ill, suffering with him [coughs] and he was the same' (Hilda) L597 '…I was one of the top [medical professional] if you know what I mean, I was on a committee, executive committee, attended meetings in London, responsible for organising this and that, and was quite an important person... I was one of the top people, and as I say, I lectured a lot and was invited to Australia, read papers there and taught in an Australian school for some time, so I was very very keen on my profession.' (Alice) L259	Loss of husbands important loss for most women except Grace and Alice. Loss of role most important for Alice. Loss of independence important for most though less for Alice, Grace and Hilda. Loss of memory for all.

		Living with an unwanted self	Florence, Alice	Florence (L810), Alice (L294, L113), Emily (L386), Vera (L165), Ruby (L113)	‘…well I do try and wear three-quarter-length things because of all these marks, cos I’ve got them all over my legs as you can see [shows me her legs]’ (Florence) L810	Embodied experience of ageing by most. Physical illness mostly spoke of and by all participants
		Adapting to a new self	Florence, Emily, Hilda, Grace, Ruby, Alice	Grace (L147, L341, L664, L688), Ruby (L187, L621, L600, L709), Hilda (L371), Alice (L744), Emily (L662), Florence (L13)	‘I just felt as if, time and all is sit down and rest myself [both laugh] so I don’t really bother now, yeah and my memory is bad for putting down something and I can’t find it, so when I put down anything now, I don’t even write it down, I say “well I’ll find it sometime!”, I say, “I’ve got too much junk in the house anyway!” [both laugh] I have to laugh, but would worry some people, don’t really bother me’ (Grace) L664	Coping mechanisms widely used by most except Vera and Lilly who were counter-case as they did not appear to use active coping mechanisms

2. A fluctuating awareness of Memory problems	All	Living with a declining memory	All	Ruby (L501, L9), Emily (L653, L677, L713), Florence (L578), Vera (L729)	‘it’s very peculiar, you can’t/ this is what is worrying me that I am definitely losing my memory, and I try, I can read the newspaper, the pieces I want to read, but I’ve found a book, and I thought I’m going to try and read some of that, to see if I can remember what it’s about, so far, I haven’t got very far, but I’m reading the words, it sounds a bit daft, I know the words but I’ve got to read them/and I go over the road and I say to John when he comes home, “what’s so and so John”, and he’ll say, “Oh mother” and then he’ll sort me out, but it’s silly things that I can’t remember, but they make your life up, you know, and I mean you can’t just forget the little things…’ (Emily) L653	All were aware of having memory problems and used denial to cope to differing extents.

		Dementia as loss of control of the mind	Alice, Florence, Emily	Alice (L344), Florence (L282), Emily (L653)	‘dementia is a very emotive word *anyhow*, erm, you feel that you haven’t got control of your mental processes, and for someone who’s highly trained, this is a *shock*, and you wonder what is going to *happen!*, and you are looking into the future, and particularly with my dear friend […] that was the chief *physiotherapist*! With a *huge* staff at [hospital] to see what has happened to her, it really sort of worried me as you can imagine, and I was wondering whether I was going to lose my reason’ (Alice)	Alice was the only participant who explicitly talked of her fear of losing control, though others alluded to it

		Denial versus Despair	All	Alice (L121), Lilly (L514, L616), Grace (L218, L581), Emily (L653), Ruby (L586), Florence (L362), Vera (L607)	'…I think it exacerbates any problems that you may have/you see, if I don't remember something, which is what my dementia is all about isn't it, it may be that I haven't heard properly, and if I say, "would you repeat that?" people will think/ there are two aspects of looking at that, either she's dotty because she's got dementia, or she hasn't heard, and often ***I*** feel it's because I haven't heard.' (Alice) L121	Conflict around admitting to self extent of memory problems for all participants. Other reasons for forgetting preferred eg, blaming others, or physical health problems.
3. Seeking sanctuary versus risking danger	All	Staying close to home to feel safe	Florence, Emily, Ruby, Grace, Vera	Emily (L925, L44), Grace (L181, L462, L601) Ruby (L222), Florence (L77)	'…that's what I'm frightened about that I might go somewhere and then you can't get back – I know it sounds a bit stupid like/like you see on films, but I don't want to be like that' (Emily) L925	Some did not want to venture far from homes for physical reasons, others through fear of getting lost/the unknown, except Lilly, Alice, Hilda

		Coping alone	Emily, Grace, Lilly, Ruby, Vera	Hilda (L373, L682, L627 Lilly (L45, L322, L336, L469), Vera (L718, L298), Ruby (L5, L27,L789, L818, L831,) Grace (L130, L577) Emily (L163, L701), Alice (L35, L697, L726), Florence (L36)	‘I just about manage, I won’t do anything that I don’t feel capable of I mean I can manage the few finances that I have, like the mortgage I suppose, cos it isn’t/ yes it is paid for!’ (Lilly) L322 ‘…well I never feel really alone, as you can see its quite busy here [looking out the window] I know quite a lot of people, I know a lot by sight and quite a few by name, and I feel living here, I could shout out of the window and yell [laughs] for help if I needed it’ (Ruby) L789 ‘…I mean I’ve got my son over there, and people here, but yes, I do feel very lonely, and when you go out, cos I just want to go out, but you’ve got to come *back* and then sometimes I feel really, really down when I come back’ (Emily) L701	Most described living alone as a struggle, apart from Alice who had lived alone for many years and had never married and Grace.

		Threat of change	Emily, Lilly	Emily (L40, L63, L909)	'…I don't know why, but somebody wants to move me out of here, but I don't want to move, and she [warden] said, "You're up to date with your rent, you're clean, and you're tidy and you are no trouble to anybody, why should you leave?"… but I kept thinking, they think I'm going a bit stupid in my head, and they'll put me in/cos they've put one lady in/ but I don't wanna be in/I don't wanna go in a home, I like it here' (Emily) L909	Emily was the only participant who explicitly talked of fearing eviction, though Lilly pondered on whether she should go into a home though this was more through feeling she could not cope.

4. Being with others: connection versus disconnection	All	Need to belong	Hilda, Alice, Ruby, Vera, Emily, Lilly, Florence	Hilda (L49, L225, L203, L287, L463, L456, L463, L667) Alice (L628) Ruby (L441, L218), Lilly (L363), Florence (L746), Vera (L399)	'…I *love* company, I always have done, you know, that's why I joined that pensioner's club on a Thursday, and which is quite nice, cos now with the nice weather coming we have *coach* trips…all over, you know Wales, and all over, beaches, … I always go out every day, or else I think I wouldn't use my mouth, you know? If you don't talk to anybody, just to the co-op up there, I don't/I walk into [nearby shops] [pause] I don't get stuck in and miserable and morbid and things like that, I don't do that, that's not me…' (Hilda) L225	All spoke in different ways about wanting contact with others.
		Privacy	Hilda, Emily, Ruby	Hilda (L209, L218, L267, L271) Lilly (L363), Emily (L3, L321), Ruby (L555)	'…well I think that's how it should be, you don't want every Tom, Dick and Harry knowing all your/ I'm not that kind of person…I'm reserved I think mmm' (Hilda) L267	Hilda and Emily spoke specifically about wanting to protect their privacy.

		Exclusion	All	Hilda (L254), Vera (L318, L718), Florence (L721), Emily (L307, L517, L831, Ruby (L167), Lilly (L114, L144)	'…she won't come back but as I say the flat is still empty and every time I hear a noise, I go out and see if there is anyone there, because they never came and told me you know!/we were quite good friends' (Florence) L721	All spoke in different ways about feeling excluded from the wider society, contact with children, friends due to eg geographical distance, mobility problems.

Appendix 7

Reflexivity

Reflexivity

In keeping with IPA philosophy I tried to minimise the impact I had upon participants, whilst attempting to build rapport and be as non-threatening as possible. Clare (2002) states social context influences how and what is disclosed in research seeking to understand the subjective experience of dementia, while Reed (2002) argued choice of methodology would affect disclosure, perhaps in interviewees perceiving one-to-one interviews as threatening. My gender, ethnicity, age, class and personal style all affect the dynamic between myself and participants and consequent extent of disclosure. Reflexivity is an ongoing process where researchers consciously understand how their values, interests and social context influence their field of study (Rolls & Relf, 2006). I am aware that a positive attachment to my grandmothers is likely to have influenced my interest in older adults, and in my wanting to understand the subjective experiences and importantly emotional world of older women. As a woman myself, perhaps I want to know what it is going to be like to be an old woman. How am I going to feel? will I be like I am now but just older and wiser?

There was a sense of participants being thirsty for contact with like-minded people and rarely getting the opportunity for this. This was particularly apparent with Alice, who upon my leaving asked if she could see me again or telephone me. I found this heart-wrenching as I admired her spirit and felt torn as I left after informing her it was unlikely she would see me again. This highlighted the dilemma of the difference between qualitative research and clinical work – in clinical work you contract a period of time/number of sessions together, so to a degree you can control how deeply you go into someone’s life and at least pace this out. In qualitative research you see someone once or in my case twice (for the initial meeting and consent, and then again for the interview) and since most of the unfolding is at the interview, the dilemma is how much to probe. I found with those participants who were bereaved (particularly Ruby and Hilda) that I should take care not to delve too deeply beneath veiled psychic pain. However, later in the course of the interview, I felt interviewees had relaxed enough into the process of the interview in order to feel safe to uncover painful material, but then after I had left, perhaps they were left with uncomfortable feelings they had not previously been consciously aware were there. I felt that Alice opened up more than she had anticipated during our interview, because of her attachment to me, and this unnerved her (she described me as an ‘empathic creature’). At the end of the interview I spent 30 minutes discussing how the interview had felt for her, as it was clear the process had brought to the surface material she had not consciously thought about, and I recommended she speak to her GP if she was worried. Despite following the ethical procedure this did leave me with painful feelings – one was a responsibility to follow through what I had started. I think this is a difficult and particularly complex issue with individuals who are lonely where one feels a human and ethical responsibility for vulnerable individuals. Booth (1998) argues for continuing relationships with research participants long after the research has ended, so as to withdraw at the individual’s pace, which though on the surface appears to go against the grain of our role as research scientists, I can understand a feeling of wanting to support and give something back to participants.

I am aware my attitudes to participants and of dementia influenced their feelings and subsequent answers given. I treated them as cogent individuals and importantly as *women*, not people with cognitive deficiencies. Consequently I feel they presented themselves as whole individuals rather than fragmented selves ravaged by dementia. During much of the interviews they talked of their lives as ordinary older women – threats to identity were spoke of more in terms of getting older, with memory problems being a problem along with other health problems rather than occupying a central position. I am unsure as to whether the de-emphasis on dementia was due to my stance, or whether this is a fact of their lives. In many cases I was forced to prompt them with the question of memory problems, and wonder if I had not, whether it would have taken an even smaller position in their narratives. The relationship between myself and participants is not dissimilar to a therapeutic relationship, requiring a highly developed capacity for emotional engagement in the client's subjective experience (Lewis 2008). The interviews provided a container in which participants could think about hitherto unthinkable aspects of their lives (i.e. the significance of dementia, earlier and future losses and associated pain) and allow them to take shape. Bearing witness to someone's life story as a third party (researcher – myself) allows the performance of an authentication process. In other words, by introducing a basic triangulation (hearing someone talk about their relationship with someone else), shows that a loss can be registered, transformed into a message to be transmitted to someone else, and accepted at some level by themselves (Leader, 2008).

As a Trainee Clinical Psychologist, IPA can initially be difficult, since we are trained to make interpretations in the immediacy of a relationship with a client in therapeutic work, whereas as a qualitative researcher, I am required not to ‘leap’, but first and foremost to say what the client or participant is saying, so that I am never far-removed from that individual’s personal experience or life-world. An important part of qualitative research with participants as those described within is to bear witness to their life stories. It has been painful at times to hear these accounts and I felt helpless because the painful truth is that there is no solution. I felt the women were looking to me for answers – thinking I might know, and of course I had no answers, only more questions. Interviewing these women I often felt torn between my role as a clinician and that of researcher, particularly when they talked of painful experiences such as losing their husbands and worries about losing their minds, and became tearful and distressed. Reflecting upon this I think in some of these interviews the boundary between those roles became blurred. I also felt conflicted as I wanted to obtain rich material, yet did not want to leave participants distressed as unconscious material became conscious, as with Alice, as discussed earlier.

Conducting this research felt like two ends of a double-edged sword - a rewarding but painful process. Emotions play a significant role in gaining recognition of and insight into the self and others, are important in motivation, learning and identity construction (Eatough & Smith, 2006). I think the extracts were selected because of their emotional intensity, and because the participants' narratives evoked a strong emotional experience in me. The inclusion of emotion in research writing is important because of its significance to people in describing their experiences and constructing meaning (Eatough & Smith, 2006), which means we feel with them - I feel I have lived with these eight women inside of me since I interviewed them last year - I have processed this material and consequently been forced vicariously to feel the pain of ageing and loss with them. Older women living alone are a rapidly expanding part of the UK population. I hope this research will consequently add another dimension to a growing body of literature on the personal, subjective experience of dementia.

Appendix 8

Notes for Contributors to ‘Dementia’